DOCUMENT RESUME

ED 444 330 EC 308 021

TITLE	National Institute on Disability and Rehabilitation Research Long-Range Plan, 1999-2003.
INSTITUTION	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
SPONS AGENCY	Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	2000-07-00
NOTE	131p.
AVAILABLE FROM	ED Pubs, P.O. Box 1398, Jessup, MD 20794-1398. Tel: 877-433-7827 (Toll Free).
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	*Agencies; *Disabilities; Federal Programs; *Long Range Planning; Models; *Organizational Objectives; *Rehabilitation; *Research and Development; Research Needs
IDENTIFIERS	*National Institute on Disability Rehab Research

ABSTRACT

This document presents the long-range (5-year) plan of the National Institute on Disability and Rehabilitation Research (NIDRR). The plan is organized around two key elements; first, a new paradigm of disability that sees disability as a product of the interaction between individual characteristics and the environment, and second, an emerging universe of disability with new disabling conditions, new causes for impairment, changing frequencies of some impairments, and new consequences of disability. Section 1 provides an introductory chapter and a chapter on current dimensions of disability. Section 2 focuses on the NIDRR research agenda with individual chapters on employment outcomes, health and function, technology for access and function, independent living and community integration, and associated disability research areas. Section 3 addresses priorities for related activities. These include: knowledge dissemination and utilization, capacity-building for rehabilitation research, and enhancing NIDRR's management of research. Four appendices provide abbreviations and acronyms, detail on the planning process and participants, a list of steering committee members, and a summary of NIDRR program mechanisms and funding patterns. (Contains 30 references.) (DB)

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NIDRR

EC 308021

Long-Range Plan 1999-2003

National Institute on Disability And Rehabilitation Research

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Director

Office of Special Education and Rehabilitative Services
National Institute on Disability and Rehabilitation Research
U.S. Department of Education

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July 2000

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Section One: Background

The *Long-Range Plan* of the National Institute on Disability and Rehabilitation Research (NIDRR) presents a five-year agenda that will advance the vital work being done in applied rehabilitation research. NIDRR intends for this plan to balance the competing demands of consumer relevance and scientific rigor, to present an agenda that is scientifically sound and accountable, and as a result, to contribute to the refinement of the nation's science and technology policy.

Two key elements on our agenda are designed to move the field forward—the new paradigm of disability and the emerging universe of disability.

The *new paradigm* is a conceptual foundation for organizing and interpreting the phenomenon of disability. The paradigm provides a way to apply scientific research to the goals and concerns of people with disabilities. This disability paradigm, which will undergird NIDRR's future research strategy, maintains that disability is a product of an interaction between individual characteristics (e.g., conditions or impairments, functional status, or personal and socioeconomic qualities) and the characteristics of the natural, built, cultural, and social environments.

The *emerging universe* is identified with new disabling conditions; new causes for impairment; differential distribution within the population; increased frequency of some impairments, including those associated with aging; and new consequences of disability, particularly related to social-environmental factors, life-span issues, and projected demands for services and supports.

Chapter 1

INTRODUCTION

Research has the potential to reinvent the future for millions of people with disabilities and their families.

—Richard W. Riley
U.S. Secretary of Education

Two developments have converged to enhance the significance of disability research. First, breakthroughs in biomedical and technological sciences have changed the nature of work and community life. These breakthroughs not only provide the potential for longer and more fulfilling lives for individuals with disabilities, they also reinforce the second major development—successful independent living and civil rights advocacy by disabled people.

This intersection of scientific progress and the empowerment of disabled people has increased momentum for disability research. These developments highlight the importance of integrating disability research into the mainstream of U.S. science and technology policy and into the nation's economic and health care policies now more than ever.

An estimated 43 million Americans are significantly limited in their capacity to participate fully in work, education, family, or community life because they have a physical, cognitive, or emotional condition that requires society to accommodate them. Public Law 101-336, the Americans with Disabilities Act (ADA) of 1990, declares that individuals with disabilities have

Photo by Tom Olin

This sculpture of Mary E. Switzer was created by Brian L. Bemisdarfer of Des Moines, Iowa, who was selected through a competition among artists with disabilities to create this artwork. This sculpture now stands in the lobby of the Mary E. Switzer building in Washington,D.C.

fundamental rights of equal access to public accommodations, employment, transportation, and telecommunications. The recognition of these rights and of society's obligation to facilitate their attainment provides individuals with disabilities with opportunities to improve their daily lives.

The mission of the National Institute on Disability and Rehabilitation Research (NIDRR) is to generate, disseminate, and promote the full use of new information that will (1) improve substantially the options for disabled individuals to perform regular activities in the community and (2) expand society's capacity to provide full opportunities and appropriate support for its disabled citizens.

NIDRR's Statutory Purpose

The inception of a federal rehabilitation research program was part of the legacy of the late Mary E. Switzer, pioneering director of the federal-state Vocational Rehabilitation (VR) program. By establishing NIDRR[1] in 1978 through amendments to the Rehabilitation Act of 1973 (Public Law 93-112), Congress realized Switzer's vision and created a research institute in the public interest. As such, NIDRR must generate scientifically based knowledge that furthers the values and goals of the disability community, leads to the creation of rational public policy, and meets the needs of service providers for information on validated and improved practices.

In founding NIDRR, Congress recognized both the opportunities for technological and scientific advances to improve the lives of individuals with disabilities and the need for a comprehensive and coordinated approach to research, development, demonstration, information dissemination, and training.

The Rehabilitation Act of 1973, as amended (with significant changes in 1992 and 1998), charged this institute with the responsibility to provide a comprehensive and coordinated program of research and related activities to maximize the inclusion and social integration, employment, and independent living of individuals of all ages with disabilities. Particular emphasis was placed on improving the coordination and effectiveness of services authorized under the act.

Other mandated activities include the widespread dissemination of research-generated knowledge and practical information to rehabilitation professionals, individuals with disabilities,

[1] Established as the National Institute of Handicapped Research, the institute's name was changed to the National Institute on Disability and Rehabilitation Research by the 1986 amendments to the Rehabilitation Act.

researchers, and others; the promotion of the transfer of rehabilitation technology; and an increase in opportunities for researchers who have disabilities or are members of minority groups.

NIDRR is ideally positioned to facilitate the transfer of new knowledge into practice as it shares administrative locations with two major service programs—the Rehabilitation Services Administration (RSA) and the Office of Special Education Programs (OSEP)—in the Office of Special Education and Rehabilitative Services (OSERS). Also, NIDRR's linkage to the greater science community through its leadership of the Interagency Committee on Disability Research (ICDR) provides an opportunity to transfer advances in basic research to the agenda for applied research and knowledge diffusion.

To further advance work in the field of applied research, the legislation requires a plan,[2] updated every five years, describing NIDRR's future research agenda. This long-range plan presents a five-year agenda focusing on consumer goals and scientific initiatives. The plan has several distinct purposes:

- to set broad general directions that will guide NIDRR's policies and use of resources as the field of disability enters the 21st century;
- to establish objectives for research and dissemination that will improve the lives of individuals with disabilities and enable annual research priorities to be formulated from it;
- to describe a system for carrying out the plan in terms of annual priorities, evaluations of the plan's implementation, and updates of the plan as necessary; and
- to place new emphasis on the management and administration of the research endeavor.

The plan was developed in collaboration with a distinguished group of NIDRR constituents—individuals with disabilities and their family members and advocates, service providers, researchers, educators, administrators, and policy-makers.

[2] As a component of OSERS within the Department of Education, NIDRR is guided by the Department's strategic plan, the OSERS' strategic plan, and NIDRR's own strategic goals and objectives as laid out in its performance plan for the Government Performance and Results Act (GPRA). The Rehabilitation Act, however, calls for a five-year program plan from NIDRR—one that identifies research needs and priorities. This *Long-Range Plan* describes the issues related to the content and management of NIDRR's research and other activities that will constitute the substantive portion of NIDRR's strategies to achieve its GPRA performance objectives.

The policy-makers included the Commissioner of the Rehabilitation Services Administration, members of the National Council on Disability (NCD), and representatives from the Department of Health and Human Services (DHHS). The plan draws upon public hearings and planning activities conducted under the prior NIDRR administration (William H. Graves, director) and on papers prepared for the plan by more than a dozen authors. The plan addresses a range of diverse needs, including:

- the needs of individuals with disabilities for knowledge and information that will enable them to achieve their aspirations for self-direction, independence, inclusion, and functional competence;

- the needs of rehabilitation service providers for information on new techniques and technologies that will enable them to help rehabilitate individuals with disabilities;

- the needs of researchers to advance the capabilities of science as well as the body of scientific knowledge; and

- the needs of society and its leadership for strategies that will enable people with disabilities to contribute to society; and

- the need to transfer findings from basic to applied research.

Accomplishments

In creating NIDRR, Congress recognized that research has contributed substantially to improvements in the lives of individuals with disabilities and their families. Individuals with disabilities live longer, have a better quality of life, enjoy better health, and look forward to more opportunities than they did 30 years ago. More advances occur every day.

Today, it is commonplace to see people in wheelchairs traveling in airplanes and private vehicles, people who are blind using computers, and people who are deaf attending the theater. Individuals who have significant disabilities have been and are being recognized as world leaders in the arts and sciences. These developments owe much to research advances at both the individual and societal levels.

Advances at the Individual Level

Research—and its use to improve practice, inform policy, and raise awareness—has changed the lives and the outlook for individuals with disabilities and their families.

For example, the life expectancy of individuals who are paralyzed from a spinal cord injury has risen continuously over the past 25 years (DeVivo & Stover 1995). One reason is that the concerted efforts of U.S. researchers, most of whom received NIDRR support, have greatly

reduced the number of severe urinary tract infections and related complications, thereby lowering renal failure as a cause of death from first to 12th place over the past two decades. Decubitus ulcers also have been a serious problem for people living with a spinal cord injury, multiple sclerosis, the aftereffects of a stroke, and other immobilizing conditions. Decubitus ulcers are destructive and costly to treat, resulting in lost workdays, high medical expenses, hospitalizations, and additional complications. Medical researchers and rehabilitation engineers have developed preventive measures, including seating, cushioning, and positioning devices; behavioral protocols; and improved treatment methods. These efforts have greatly reduced the time needed for medical treatment of decubiti and the cost of this treatment.

Rehabilitation engineering research has been responsible for the application of new materials in the design of wheelchairs and orthotic and prosthetic devices; these new materials render these technologies comfortable and serviceable, and allow their#=sers to accomplish many important personal goals. For example, wheelchair racers using the newest sports wheelchairs can complete races longer than 800 meters faster than Olympic runners. In the Paralympics, runners using prosthetic legs have repeatedly demonstrated impressive speeds. In everyday life, people who use wheelchairs have benefited from lightweight, transportable chairs as well as powered chairs, which greatly increase the independence of some users.

Advances at the Environmental-Societal Level

In the last two decades, NIDRR has participated in an unprecedented expansion of opportunities and possibilities for people with disabilities. During this period, technology has greatly enhanced the accommodation of disabilities, self-awareness has increased the expectations of and for people with disabilities, and advocacy has resulted in the recognition of the rights of people with disabilities to societal access and reasonable accommodations.

NIDRR-supported research also has facilitated the inclusion of people with mental retardation and those with emotional disabilities in communities, workplaces, and lifelong learning experiences. In doing so, NIDRR researchers have documented patterns of deinstitutionalization; developed techniques for behavior management that have enabled individuals to leave institutions and live and work in the community; strengthened self-advocacy and peer-support programs; developed technological solutions to improve access to housing, communications, and work; and developed strategies to increase the employment of individuals with

cognitive and emotional disabilities and to support families of the disabled in their important role.

Today's research on the application of the principles of universal design to the built environment, information technology and telecommunications, transportation, and consumer products is based on the concept of an environment that is usable by people with a very broad range of function. For example, after years of research, all television sets are now equipped with decoders that allow people with hearing loss to access most programs. In addition, ergonomic research undergirds the development of workplace designs and the standards for building codes, consumer products, and the telecommunications infrastructure. These advances have been instrumental in changing the disability paradigm and expanding the word *disability* to include environmental as well as individual factors.

NIDRR's research activities also have led to the development of small businesses in hearing aids, prosthetics, communication devices, and instructional software. NIDRR research provides an important stimulus in a field of orphan products with small markets.

Expectations for the Future: A New Paradigm of Disability

The identification of trends in the distribution of disabilities, the emergence of new disabilities, and the prevalence of disabilities among the nation's aging population further challenge the disability research field. The research field must develop ways to measure and address the impact of environmental factors on the phenomenon of disability.

NIDRR has led the way in the research for a new conceptual foundation to organize and interpret the phenomenon of disability—a new paradigm of disability.

This paradigm is a construction of both the disability and scientific communities and provides a mechanism to apply scientific research to the goals and concerns of individuals with disabilities. The new paradigm of disability is neither entirely new nor entirely static. Thomas Kuhn (1962) viewed a paradigm as a time-limited model for framing problems and solutions within any discipline. The term paradigm is used above in the quasi-popular sense it has acquired over the last 40 years—to indicate a basic consensus among investigators of a phenomenon that defines the legitimate problems and methods of a research field.

NIDRR posits that the paradigm in this case applies not to a single field, but to a single phenomenon—*disability*—as it is investigated by multiple disciplinary fields. The disability paradigm that undergirds NIDRR's research strategy for the future maintains that disability is a

product of an interaction between the characteristics of the individual (e.g., conditions or impairments, functional status, or personal and social qualities) and the characteristics of the natural, built, cultural, and social environments. The construct of disability is located on a continuum from enablement to disablement. Personal as well as environmental characteristics may be enabling or disabling, and the relative degree fluctuates, depending on condition, time, and setting. Disability is a contextual variable, dynamic over time and circumstance.

Environments may be physically accessible and inaccessible, culturally inclusive and exclusive, accommodating and unaccommodating, and supportive and unsupportive. For example, on a societal level, institutions and the built environment have been designed for a limited segment of the population. Researchers should explore new ways of measuring and assessing disability in context, taking into account the effects of physical, policy, and social environments, and the dynamic nature of disability over the lifespan and across environments.

Perhaps the new paradigm can be understood best by comparing it with the paradigm it replaces and by clarifying the importance the new paradigm has for all aspects of research and policy (see table 1). The old paradigm, which was reductive to medical condition and is reflected in many aspects of the nation's policy and service delivery arenas, has presented disability as a deficit in an individual that prevents the individual from performing certain functions or activities. This underlying assumption about disability has affected many aspects of research, rehabilitation, and services.

The new paradigm of disability is integrative and holistic, and focuses on the whole person functioning in an environmental context. This new paradigm of disability is reflected in the ADA and sets a goals framework for research, policy, and the delivery of services and supports relative to disability. The new paradigm, with its recognition of the contextual aspect of disability—the dynamic interaction between individual and environment over the lifespan that constitutes disability—has significant consequences for NIDRR's research agenda over the next decade. These consequences include changes in the ways disability is defined and conceptualized, new approaches for measuring and counting disability, changes in the focus of research, and changes in the way research is managed and conducted.

Issues Regarding Definition

One of the fundamental consequences of the new paradigm is the need to change definitions. The definition of disability is critical to building a conceptual model that identifies relevant components of

Table 1. Contrast of Paradigms

	Old Paradigm	New Paradigm
Definition of Disability:	An individual is limited by his or her impairment or condition.	An individual with an impairment requires an accommodation to carry out life activities.
Strategy to Address Disability:	Fix the individual, correct the deficit.	Remove barriers, create access through accommodation and universal design, and promote wellness and health.
Method to Address Disability:	Provide medical, vocational, or psychological rehabilitation services.	Provide support (e.g., assistive technology, personal assistance services, job coach).
Source of Intervention:	Professionals, clinicians, and other rehabilitation service providers.	Peers, mainstream service providers, and consumer information services.
Entitlements:	Eligibility for benefits based on the severity of the impairment.	Eligibility for accommodations seen as a civil right.
Role of Disabled Individual:	Object of intervention, patient, beneficiary, research subject.	Consumer or customer, empowered peer, research participant, and decision-maker.
Domain of Disability:	A medical problem.	A socioenvironmental issue involving accessibility, accommodations, and equity.

Note: This table is adapted from materials prepared for this *Long-Range Plan* by Gerben DeJong and Bonnie O'Day from the National Rehabilitation Hospital Research Center in Washington, D.C.

disablement and their relationships to one another, and the dynamic mechanisms by which they change.

Typically, definitions of disability have varied, depending on their intended use. From a research perspective, the definitions used to count and describe disabled people have been important, while from the policy perspective, these definitions are critical to establishing eligibility for benefits and services.

The majority of federal definitions of disability—including those in the Rehabilitation Act, the ADA, and the National Health Interview Survey (NHIS)—originated from the old paradigm. These definitions all attribute the cause of limitations in daily activities or social roles to characteristics of the individual, that is, conditions or impairments. Even the ADA, which promotes accessibility and accommodations, connects the disability with the individual. This is understandable not only because changing a paradigm is complex and takes a long time, but also because there has been no system to define, classify, and measure the environmental components of disability or a model to describe and quantify the interaction of environmental and individual variables.

This need to change definitions must be addressed by activities, such as the attempt to revise the *International Classification of Impairments, Disabilities, and Handicaps* (World Health Organization 1980), to better define and measure the factors external to an individual that contribute to his or her disability.

Measurement Issues

Sources of data, including demographic studies and national surveys, should be adjusted to reflect new definitions or concepts and to take into account the contextual variables in survey sampling techniques. Survey questions must reflect environmental factors as well as individual factors such as socioeconomic characteristics or impairments. Under the new paradigm, questions about employment status, for example, should focus on the need for accommodations as well as on the existence of an impairment. New measures must enable researchers to predict and understand changes in the prevalence and distribution of disabilities that illustrate the link between underlying social and environmental conditions—poverty, race, culture, isolation, and the age continuum—and the emergence of new causes of disability, new disability syndromes, and the differential distribution of disabilities among various populations in our society.

Concern is focused increasingly on vulnerable populations, as researchers find more evidence that disability and the risk of disability are disproportionately concentrated

in specific populations: those in poverty, those who lack access to state-of-the-art preventions or interventions, and those who are exposed to additional external or lifestyle risk factors. There are new impairments, exacerbated impairments, and new etiologies that are associated with socioeconomic status, education levels, access to health care, nutrition, living conditions, and personal safety.

Individuals from racial, linguistic, or cultural minority backgrounds are more likely to live in poverty and to lack adequate nutrition, prenatal and other health care, access to preventive care, and health information. These individuals also experience more incidents of interpersonal violence and intentional injury. The new paradigm's recognition of environmental factors leads to a focus on underserved minority populations—part of the emerging universe of disability to be discussed in "Chapter 2."

New Focus of Research Inquiries

The new paradigm adds or increases the relative emphasis on certain areas of inquiry. Research must develop new methods to focus on the interface between people and society. It is not enough simply to shift the focus of concern from the individual to the environment. What is needed are studies of the dynamic interplay between people and environment; of the adapting process, by the society as well as by the individual; and of the adaptive changes that occur during a person's lifespan. The aging of the disabled population in conjunction with quality of life issues dictates a particular focus on the prevention and alleviation of secondary disabilities, co-existing conditions, and health maintenance over the lifespan. Research must focus on the development and evaluation of environmental options in the built environment and the communications environment. In developing these options, researchers will incorporate universal design and modular design principles and the use of assistive technology.

Research will lead to a better understanding of the context and trends in our society that affect the total environment in which people with disabilities live and in which disability will be manifested. These influences include economy and labor market trends; social, cultural, and attitudinal developments; and new technological developments. Research must develop ways to enable individuals with disabilities to compete in the global economy, including education and training methods, job accommodations, and assistive technology.

Researchers must understand the public policy context in which disability is addressed, ignored, or exacerbated. General fiscal and economic policies, as well as more specific policies on employment, the delivery and financing of health care,

income support, transportation, social services, telecommunications, institutionalization, education, and long-term care are critical factors influencing disability and disabled people. Their frequent inconsistencies, contradictions, and oversights can inhibit the attainment of personal and societal goals for people with disabilities.

Research Management

The new paradigm requires new models for managing the research enterprise—including stakeholder participation, interdisciplinary and collaborative efforts, more large-scale and longitudinal research, and new research methodologies to conduct meaningful studies in the emerging policy environments. NIDRR will expand training in disability and rehabilitation research to include disciplines such as architecture and business. There will be new venues for conducting research and a need for validated methodologies to conduct research on dynamic person-environment interactions, often under constricted circumstances. Through training programs, the disability and rehabilitation research field also should work to increase the number of disabled and minority researchers.

The role of disabled consumers in research under the new paradigm, as well as in policy and services, is proactive and participative. Consumers have a role in shaping their environments and in managing the supports and services they require. Research must be more inclusive and participatory, involving not only consumers but also other stakeholders in understanding and interpreting research; in disseminating and applying research findings; and in planning, conducting, and evaluating research. Consumer satisfaction with research and services will be subject to assessment.

Moreover, interdisciplinary and collaborative research is important for explicating the multidimensional qualities of disability. Only through research coordination and collaboration can basic research findings be translated into the knowledge base of disability research.

Regardless of its auspices, research is a cumulative and integrative process; new knowledge comes from many sources, often in response to concerted pursuit, but also sometimes serendipitously. Research is often slow-moving and always painstaking; one of the ironies of the research effort is that a disproved hypothesis may constitute a successful project, particularly if it diverts the time and resources of others from an unfruitful direction. As one participant in the planning process said, "Sometimes the new questions you stimulate are more important than the ones you answer in your research project." NIDRR is pleased to have collaborated with

many other federal and private agencies that sponsor various types of disability and rehabilitation research, and is committed to making research an inclusive, collaborative, and coordinated undertaking.

Organization of the *Long-Range Plan*

This introductory chapter has set the framework for understanding NIDRR's mission and approach. After the next chapter, "Dimensions of Disability," "Section Two" will discuss an agenda for research that will provide opportunities for leadership and innovation. NIDRR will implement this research agenda in conjunction with excellent management strategies, a dynamic program of knowledge dissemination, and a vigorous effort to build the capacity of the field through training researchers and users of research. Section Three will focus on these activities.

NIDRR intends this five-year plan to balance the competing demands of consumer relevance and scientific rigor. To this end, the research agenda is designed to be responsive, scientifically sound, and accountable. Ultimately, NIDRR aims to help refine the nation's science and technology.

Chapter 2

DIMENSIONS OF DISABILITY

Policy issues at the forefront of the disability agenda require accurate data, routinely repeated measures, sophisticated analysis, and broad dissemination.

—National Council on Disability
Action Steps for Changes to Federal Disability Data Collection Activities, *draft report, Sept. 19, 1997*

This chapter of the *Plan* presents NIDRR's operative definitions of disability, discusses several analytical frameworks for categorizing disability, and highlights deficits in current definitions and data collection. The chapter then presents data about the prevalence and distribution of disability in the nation and includes selected demographic data related to the major NIDRR goals of independence, inclusion, and employment.

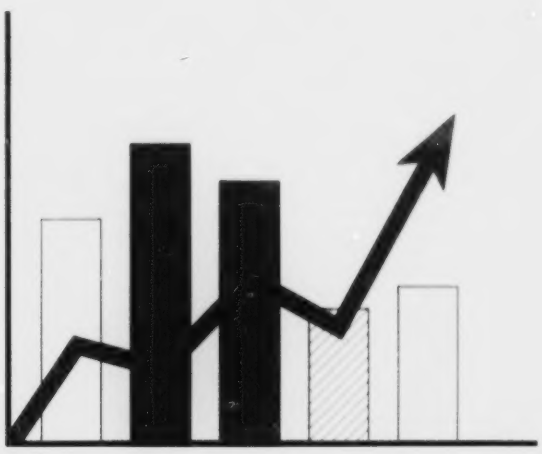
Definitions and Concepts of Disability and Disablement

The definition of an individual with a disability under which NIDRR operates is contained in the Rehabilitation Act of 1973, (Public Law 93-112) as amended. The law describes a person with a disability as follows:

...any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment (29 U.S.C. 706(8)(B)).

This definition is similar to those contained in the ADA, the Assistive Technology Act of 1998, and the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act).

The impairments that cause limitations in activities may relate to genetic conditions or to acquired diseases or traumas. The extent of a disability and the conditions



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associated with a disability are significant to individuals, to families, and to the nation.

Prevailing definitions, based in statute and supporting program authorities, clearly do not reflect new paradigm concepts of disability. Nearly all definitions identify an individual as disabled based on a physical or mental impairment that limits the person's ability to perform an important activity. Note that the other possibility—that the individual is limited by a barrier in society or the environment—is never considered. This plan suggests that it is useful to regard an individual with a disability as a person who has an impairment that requires an accommodation or intervention rather than as a person who is limited solely by a condition. This new approach derives from the interaction between personal variables and environmental conditions. Because accommodations can address person-centered factors as well as socioenvironmental factors, a need for accommodation is a more adaptable concept for the new paradigm.

The various definitions of disability that have formed the basis for both program eligibility and survey data collection do not have explanatory power for research purposes. The field of disability research lacks a widely accepted conceptual foundation to measure it as well as consistent definitions for data collection. In recent years, however, a number of efforts to develop conceptual frameworks to organize information about disability have been initiated (see table 2).

Among these efforts are the following:

- The ICIDH, which the WHO developed in 1980, was designed to provide a framework to organize information about the consequences of disease. An ongoing revision process is considering social, behavioral, and environmental factors to refine the concept of *handicap*.

- The Nagi model (Nagi), was presented by the Institute of Medicine (IOM) in its 1991 *Disability in America* report (Pope & Tarlov). The model was revised in the 1997 report, titled *Enabling America* (Brandt & Pope). The 1991 IOM Report posits that a disability is a function of the interaction of individuals with their social and physical environments. The revised Nagi model describes the environment as including the natural environment, the built environment, the culture, the economic system, the political system, and psychological factors.

- The new Nagi model includes a state of *no disabling condition*. The state of *disability* is not included because disability is not viewed as inherent in the person, but

rather as a function of the interaction of the individual and the environment.

- The schematic adopted by the National Center for Medical Rehabilitation Research (NCMRR) in its *Research Plan* (National Institute of Child Health and Human Development) added the concept of societal limitation.

Continuum of Enablement—Disablement

The most widely used conceptual frameworks applied to disability and rehabilitation research share a continuum that progresses from some underlying etiology or disease to limitations in physical or mental function. These functional limitations, when combined with external or environmental conditions, may lead to some deficit in the performance of daily activities or expected social roles.

In *Enabling America*, the IOM urges the adoption of a new conceptual framework as a model for the enablement-disablement process (Brandt & Pope). This model has the advantage of identifying components of person-centered and environment-centered variables. The IOM framework identifies four categories of individual factors (person, biology, behavior, and resources) and nine categories of external environment factors (natural, culture, engineered environments, therapeutic modalities, health care delivery system, social institutions, macro-economy, policy and law, and resources and opportunities).

NIDRR research focuses on crucial areas of functional loss, disability, and socioenvironmental aspects of the continuum. In keeping with the new paradigm, NIDRR emphasizes the importance of explicating the connection between the person and the environment, an interface that determines the disabling consequences of impairments and related conditions. This study of the dynamic interaction among various individual and environmental variables requires NIDRR to increase its attention to shaping the structure, management, and capacity for research. Methodologies are needed, often in an interdisciplinary context, that can illuminate multiple facets of disablement and enablement from numerous perspectives.

Limitations in Federal Data Sources

The various federal data collection efforts that assess the extent and distribution of disability in society are less than ideal for measuring the population that meets the NIDRR definition of an individual with a disability. These efforts generally can be categorized as one of two types (1) program data, which focus on the recipients of federal benefit or service programs, or (2) national surveys that focus on perceived limitations in activities caused by health conditions. Both program and

Table 2. Concepts in Models of Disability

ICIDH	Nagi/1991 IOM	NCMRR
Disease – Something abnormal within the individual; etiology gives rise to change in the structure and function of the body.	**Active pathology** – Interruption or interference of normal bodily processes or structures.	**Pathophysiology** – Interruption or interference with normal physiological and developmental processes or structure.
Impairment – Any losses or abnormalities of psychological, physiological, or anatomical structure or function at the organ level.	**Impairment** – Anatomical, physiological, mental or emotional abnormalities or losses.	**Impairment** - Losses or abnormalities of cognitive, emotional, physiological, or anatomical structure or function, including losses or abnormalities that are not those attributable to the initial pathophysiology.
Disability – Any restriction or lack (resulting from an impairment) of the ability to perform an activity in the manner or within the range considered normal for a human being.	**Functional limitation** – A restriction or lack of the ability to perform an action or activity in the manner or range considered normal—which results from an impairment.	**Functional limitation** - A restriction or lack of the ability to perform an action in the manner or within the range consistent with the parts of an organ or organ system.
Handicap – A disadvantage resulting from an impairment or disability that limits or prevents fulfillment of a role considered normal for a particular age, sex, and sociocultural factors.	**Disability** - An inability or limitation in performing socially defined activities and roles expected of individuals within a social and physical environment.	**Disability** - An inability or limitation in performing tasks, activities, and roles to levels expected within the physical and social context.
		Societal limitation – Restrictions attributable to social policy and barriers (structural or attitudinal) that limit fulfillment of roles and deny access to opportunities that are associated with full participation in society.

Note: Information in column 1 is from *International Classification of Impairments, Disabilities, and Handicaps*, by the World Health Organization, 1980, Geneva, Switzerland: World Health Organization.
Information in column 2 is from Disability Concepts Revisited: Implications for Prevention, by S.Z. Nagi, 1991, (p. 7) in *Disability in America: Toward a National Agenda for Prevention* by A. M. Pope and A. R. Tarlov (Eds.), 1991, Washington, DC: National Academy Press.
Information in column 3 is from *Research Plan for the National Center for Medical Rehabilitation Research*, (p. 33), by the National Institute of Child Health and Human Development (1993) (NIH Publication No. 93-3509), Washington, DC: U.S. Government Printing Office.

survey data focus on the physical or mental impairment as the cause of the limitation. This is a reductionist approach that discounts social and environmental factors or assumes that these factors are subsumed within individual attributes.

The National Health Interview Survey (NHIS) and the Survey of Income and Program Participation (SIPP) are the two most widely used sources of survey data to describe the population of individuals with disabilities. Researchers currently are analyzing data from the Disability Supplement to the NHIS; these analyses will yield much-needed information on people with disabilities. The development of the Disability Supplement was a collaborative effort by federal agencies concerned with disability issues. While the Disability Supplement data have enormous value, the supplement, like other data sources, doesn't measure the environmental factors (social or physical) that contribute to disabilities, nor the interaction between the person and his or her environment.

Federal data collection efforts—including the Census, the NHIS, the SIPP, the Current Population Survey (CPS), and many other program-specific or topical data collection methods—not only fail to address important new concepts of disability, but also are limited in other ways. The sampling procedures may result in the exclusion of low-incidence disabilities and insufficient information about minority populations; self-reporting leads to underreporting many conditions; and survey formats frequently are inaccessible to people with cognitive, sensory, or language limitations. Many federal data collection efforts, as well as most private ones, do not routinely include information about people with disabilities in their data collection and reporting. Improving data quality and availability will be a key goal of NIDRR over the next five years.

Particular problems exist in defining and quantifying disability in children. Many service program staff rely on diagnostic categories for eligibility, and even those who have attempted a functional approach have had difficulty assessing the effect of context, expectations, transactions with adults, chronicity, and duration in determining the extent of disability among children.

The Office of Special Education Programs (OSEP) administers the Individuals with Disabilities Education Act (IDEA). A U.S. Department of Education effort, IDEA mandates that schools have the full range of services necessary to provide a free and appropriate public education for children with disabilities. According to OSEP's 1995-96 IDEA annual report to Congress, 5.6 million disabled children (ages 3 to 21) received educational services. Approximately

one-half of these children were identified as having specific learning disabilities. Other high-incidence disabilities included speech and language impairments, mental retardation, and serious emotional disturbances.

Because OSEP and other Department of Education offices focus their research on activities based in the educational system—including the development of curricula and teaching methods, as well as teacher training—NIDRR has concentrated its research on other areas concerning disabled children. These issues include family-child relations, social relationships, community integration, medical technologies that may replace or substitute for function, accommodations, and support available to families. NIDRR research also has a role in addressing the critical problems of succeeding in the transition from school to adult life in the community, to work, and to adult service systems. In a broader context, it is important to note that 5.5 percent of all American families have one or more children with a disability (LaPlante, Carlson, Kaye, & Wenger). Children with disabilities are more likely to live in low-income families and in families headed by single mothers.

Prevalence of Disability

Disability research is very important due to the fact that disabilities are so frequent and widespread in the United States. The following data about disabilities were selected because of their relevance to NIDRR's specific priorities and to the overall objectives of this *Plan*.

The 1994 NHIS estimated that 15 percent of the noninstitutionalized civilian population—some 38 million people—were limited in activity due to chronic conditions (Adams & Marano 1995). The Institute of Medicine interpolated the NHIS data to indicate that 38 percent of disabilities were associated with mobility limitations, followed by chronic disease (32 percent); sensory limitations (8 percent); intellectual limitations (7 percent); and other conditions (15 percent) (Pope & Tarlov 1991). The SIPP identified 48.9 million people who reported themselves as limited in performing functional activities or in fulfilling a socially defined role or task. Of these, 24.1 million people were identified as having a "severe disability" (Kraus, Stoddard, & Gilmartin 1996). Both surveys excluded people in nursing homes or institutions, who would be expected to have a high rate of disability. Including that population through extrapolation has led to the commonly cited figures of 43 million to 48 million Americans with disabilities.

Both the NHIS and SIPP focus on limitations in performing major life activities that are due to a physical or mental condition. Both groups also provide data, however, on

people who are limited in performing or unable to perform activities of daily living (ADLs)—such as eating, bathing, dressing, toileting, or moving around without assistance from others or the use of devices. Data are also collected on those who have trouble with instrumental activities of daily living (IADLs)—such as performing basic home care, shopping, preparing meals, telephoning, and managing money. Approximately 8 million people reported having difficulty with ADLs, and some 4 million of them said they needed the assistance of another person (McNeil 1993).

The range of these estimates—from approximately 4 million people who need help simply to sustain their lives to the 40 million who report any kind of activity limitation—illustrates the risks in discussing the disabled population as a homogeneous group. More refined data are needed to assess the needs for medical and health care, vocational rehabilitation and employment assistance, supports for living in the community, and assistive technology.

Demographics of Disability: Age, Gender, Race, Education, Income, And Geography

Disability is distributed in many ways throughout the population, according to characteristics such as age, gender, race, ethnicity, and both the region and size of the locality in which a person resides. The educational level is inversely correlated with the prevalence of disability. Poverty is a key factor, both as a contributing cause and a result of disability. Table 3 presents NHIS data on sociodemographic correlates of activity limitations. These data indicate that disability is very likely linked to other social factors, reinforcing the need to address disability in a broad context.

Emerging Universe of Disability

NIDRR has begun to focus on an *emerging universe* of disability, in which the conditions associated with disability, their distribution in the population, and their causes and consequences are substantially different from those in the traditional disability population.

This emerging universe is identified with new disabling conditions; new causes for impairments; differential distributions within the population; increased frequency of some impairments; and different consequences of disability. Such consequences relate to social-environmental factors, lifespan issues, and projected demands for services and supports.

Researchers have identified a *new morbidity* (Baumeister, Kupstas & Woodley-Zanthos 1993) in which the cluster of factors associated with poverty—such as poor education, poor medical care, babies with a low birth weight, a lack of prenatal care,

substance abuse, interpersonal violence, isolation, occupational risks, and exposure to environmental hazards—have a high correlation with the existence of impairments, disabilities, and exacerbated consequences of disabilities.

For example, the leading cause of mental retardation is no longer RH-factor incompatibility, but may be related to any factor associated with high-risk births, which are more common among low-income mothers. Interpersonal violence accounts for the rising incidence of certain conditions, especially spinal cord injury and traumatic brain injury, among inner-city minority populations. These developments have enormous implications for research problems to be addressed and for future demands for various types of services.

New illnesses or conditions have emerged in recent years; some, but by no means all, are poverty-related. AIDS, Attention Deficit Hyperactivity Disorder (ADHD), violence-induced neurological damage, repetitive motion syndrome, chronic fatigue syndrome, childhood asthma, drug addiction, and environmental illnesses are all either relatively new conditions or ones of increasing prevalence and severity in society. Additionally, the aging of the population, given the higher rates of many disabilities among older people, is another demographic factor that will influence issues to be addressed by applied research. Many emergent disabilities, including those attributed to violence, abuse, and poverty, have a higher incidence among women and are particularly likely to affect women who already have disabilities.

As new causes of disabilities emerge, the new paradigm of disability clearly provides a progressive approach to successfully addressing environmental and social barriers for people with disabilities. These new issues have implications not only for disability research and services, but also for public health and prevention activities.

Disability, Employment, and Independent Living

Because of NIDRR's statutory concern with improving employment outcomes for people with disabilities, it is valuable to present a brief overview of the employment status of people with disabilities.

LaPlante & Carlson (1996) reported that 19 million Americans (ages 18 to 69) with an impairment or health problem were unable to work or were limited in the amount or type of work they could perform. According to the CPS, about 10 percent of the population between ages 16 and 64 had work limitations (different age ranges reflect changing concepts of *working age*) (LaPlante, Kennedy, Kaye, & Wenger 1996). Back disorders, heart disease, and arthritis

Table 3. Degree of Activity Limitation Due to Chronic Conditions, by Demographic Characteristics: 1994

Characteristic	All people (in thousands)	In Percentages			
		With Activity Limitation	Unable to Carry Out Major Activity	Limited In Amount Or Kind Of Major Activity	Limited, But Not In Major Activity
All persons	259,634	15.0	4.6	5.7	4.7
Age					
Under 18 years	70,025	6.7	0.7	4.2	1.8
18-44 years	108,178	10.3	3.2	3.9	3.1
45-64 years	50,405	22.6	9.2	7.9	5.5
65-69 years	9,685	36.7	16.7	11.9	7.3
70 years and older	21,340	38.9	8.1	12.6	19.3
Sex					
Male	126,494	14.4	4.8	5.3	4.3
Female	133,139	15.7	4.4	6.1	5.2
Race					
White	214,496	15.1	4.4	5.8	4.9
African American	33,035	16.3	6.3	6.2	3.8
Family Income					
Under $10,000	23,363	28.0	11.2	9.9	6.9
$10,000 - $19,999	37,271	21.1	7.3	7.7	6.2
$20,000 - $34,999	54,171	14.8	4.1	6.0	4.7
$35,000 or more	100,302	9.4	1.9	3.9	3.6
Geographic Region					
Northwest	50,610	14.3	4.3	5.6	4.3
Midwest	63,238	14.6	3.9	6.0	4.6
South	88,088	16.1	5.3	6.0	4.8
West	57,697	14.7	4.6	5.0	5.0
Place of Residence					
Metropolitan Statistical Area (MSA)	203,079	14.3	4.4	5.5	4.5
Central city	79,510	15.8	5.4	5.9	4.5
Not central city	123,570	13.4	3.8	5.2	4.5
Not MSA	56,554	17.6	5.4	6.6	5.6

Source: P. F. Adams and M.A. Marano, Current Estimates from the National Health Interview Survey, Series 10, No. 193, from Tables 67-68, Hyattsville, MD: National Center for Health Statistics, 1994.

were frequently reported as major causes of work disability (LaPlante & Carlson 1996). However, mental illness is one of the most work-disabling conditions; data have shown that among adults with a serious mental illness (an estimated 3.3 million people), 29 percent are unable to work, and 18 percent are limited in their ability to work (Barker, Manderscheid, Hendershot, Jack, Schoenborn, & Goldstrom 1992).

While the presence of any disability reduces the likelihood of employment, the effect is closely tied to the severity of the disability. The SIPP estimates that among people 21 to 64 years of age, the employment rate was 81 percent for people with no disability, 67 percent for people with a disability that was not severe, and 23 percent for people with a severe disability (McNeil 1993). Only 21 percent of people needing personal assistance with ADLs or IADLs were employed (U.S. Bureau of the Census 1998). The unemployment rate for people with disabilities, which counts only those people in the labor force, was 12.6 percent, more than twice the unemployment rate of nondisabled Americans (Stoddard, Jans, Ripple, & Kraus 1998).

Disabled people who work full-time typically earn less than nondisabled workers, with the earnings gap widening with age and the severity of the disability. People with disabilities who do not work may qualify for income support payments under Social Security Disability Insurance (SSDI) (if they have a work history) or Supplemental Security Income (SSI). As of January 1996, 5 million people received SSDI benefits, including 4.2 million disabled workers; 686,300 disabled adult children; and 173,800 disabled widows and widowers (Social Security Administration 1996). A 1993 report cited mental disorders as the most frequent cause of disability (35 percent), followed by musculoskeletal, circulatory, and nervous system disorders (Social Security Administration 1993).

At the end of 1993, about 3.8 million people under age 65 received SSI benefits due to disability and poverty (Kochhar & Scott 1995). More than one-half of these people had either mental retardation or mental illness. The Social Security Administration (SSA) has noted a sharp increase in the number of disabled SSI recipients, an increasing proportion with mental illness, and a growing number who enter the rolls as children and remain for long periods (Kochhar & Scott 1995).

Many of these increases in the numbers of SSDI and SSI recipients can be attributed to the following: changing the program (such as initiating different eligibility requirements and outreach), shifting from other income support categories, changing the stability of employment and private health insurance, and bundling of health insurance coverage with income supports. Eligibility for

public health insurance is generally tied to the receipt of income transfer payments from a public income support program.

Data elements about residential status, family composition, and the need for personal assistance services illuminate some of the characteristics of the disabled population. Of the estimated 48.9 million people with disabilities from the SIPP data, 32.5 million own their own homes and 16.4 million rent (McNeil 1993). An estimated 9.8 million live alone, and more than 27 million people with disabilities are married. An estimated 8.3 million individuals with disabilities live in a household with their spouse and children under age 18, while an estimated 1.9 million are single parents with disabilities.

An estimated 20.3 million families, or 29.2 percent of all 69.6 million families in the United States, have at least one relative with a disability (as measured by having an activity limitation). This rate for families is much higher than the rate for individuals having a disability. Further, there appears to be a clustering of people with disabilities in families and households, with a much higher-than-expected likelihood of both adult partners having disabilities and a greater-than-average chance that children with disabilities will live with one or more parents with disabilities. Families headed by adults with disabilities are more likely to live in poverty or to be dependent on public income support programs.

Conclusion

This chapter of the *Long-Range Plan* highlighted some important disability statistics that illustrate the scope of disability in the United States. Throughout the *Plan*, significant data also are interspersed about the use of assistive technology, access to health care, labor force participation, and community living. In addition, Chapter 7 addresses the need for future research in disability data collection.

Overall, the current data on disabilities provide both a picture for concern and a cause for optimism. People with disabilities tend to have lower-than-average educational levels, low income levels and high unemployment rates, especially people with severe disabilities. Moreover, the relationship between disability and poverty tends to be bi-directional, with the conditions of poverty creating a high risk for disability and disability itself leading to poverty.

At the same time, it is clear that more individuals with disabilities are completing high school and college, and education is closely correlated with employment and independence. Increasingly, individuals with disabilities are living in the community, marrying, and raising families. These individuals may receive increased attention from

businesses as they constitute a market for accessible housing and adaptive devices, recreation, adult education, accommodated travel, health care, and other services.

Providers of goods and services in the marketplace—whether purveyors of travel and recreation, assistive devices, clothing, or any other commodities—want estimates of the size and characteristics of the potential disability market for their products. It is becoming increasingly important to provide these market estimates and to package data to meet the needs of manufacturers and distributors, so businesses can expand the variety of goods and services available to people with disabilities.

It is also true that, while the presence of a disability may present significant challenges to individuals and families, society demonstrates a growing capacity to assist people with disabilities to meet their needs for equity and access through new discoveries in research, improved service methods, and informed policy decisions.

Section Two: NIDRR Research Agenda

Several significant principles guide this discussion of NIDRR's research agenda. First, a research agenda must allow for flexibility to facilitate response to evolving research questions. In a world where technological innovations and new research results can affect the relevance of other ongoing research, NIDRR must be ready to update its response to changes in the field as they occur and to readily incorporate its response into the research program. NIDRR research will focus on demonstrating outcomes that expand the knowledge base and that meet the needs of people with disabilities. Documenting outcomes is critical to demonstrating value, which is increasingly important in a resource-limited society. As mentioned earlier, NIDRR-sponsored research also must balance the demands of consumers for useful solutions with the demands of science for careful and rigorous methodology.

NIDRR's prior research efforts have addressed most aspects of the lives of people with disabilities. Over time, a framework has emerged that relates these aspects to maximum independence and participation. As explained in previous sections, the new paradigm of disability emphasizes the contextual nature of disability as a product of individual and societal factors. This important paradigm shapes the future research agenda described in this section. This agenda represents our current best thinking about those areas where NIDRR research can help people with disabilities maximize their independence and become fully integrated into American society. These areas include Employment Outcomes, Health and Function, Technology for Access and Function, Independent Living and Community Integration, and Associated Disability Research Areas.

Chapter 3

EMPLOYMENT OUTCOMES

With the ADA, we began a transformation of the proverbial ladder of success for some Americans into a ramp of opportunity for all Americans. Yet, so many Americans with severe disabilities are still unemployed that it is clear we have many more steps to take before people with disabilities have full access to the American dream.

—Tony Coelho, chairman
President's Committee on
Employment of People
with Disabilities

Overview

Unemployment and under-employment among working-age Americans with disabilities are ongoing and seemingly intractable problems. Data from the Census Bureau on the labor force status of people ages 16 to 64 in fiscal year 1996 highlight the magnitude of this problem. While four-fifths of working-age Americans are in the labor force and more than three-fourths are working full-time, less than one-third of people with disabilities are in the labor force, and less than one-quarter are working full-time (see figure 1). Fully two-thirds of working-age people with disabilities are not in the labor force. Some research suggests that a substantial portion of this staggering figure can be attributed to disincentives inherent in social and health insurance policies, to discouragement, and to a lack of physical access to jobs.

While the comparative rates of labor force participation and full-time employment are two indicators of the workforce status of individuals with disabilities, a comparison of earnings is even more striking. In figure 2, SIPP data illustrate the discrepancies in earnings between disabled and nondisabled working men and women.

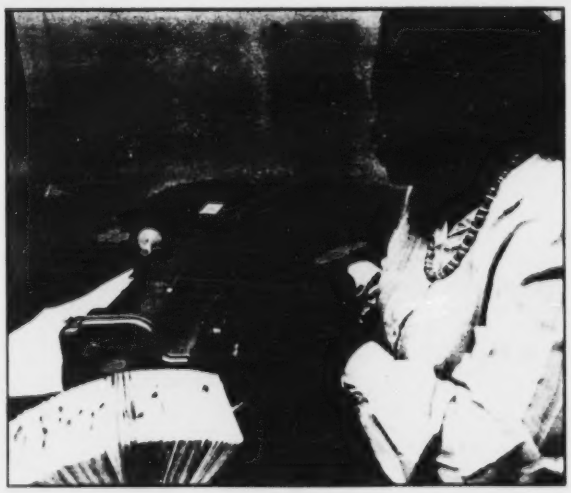
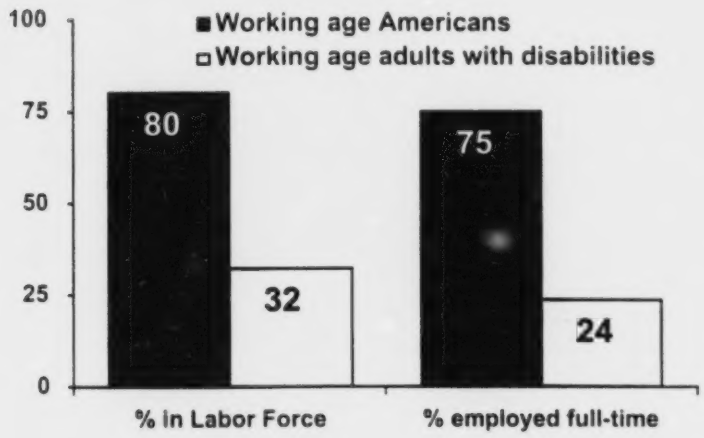


Photo by Tom Olin

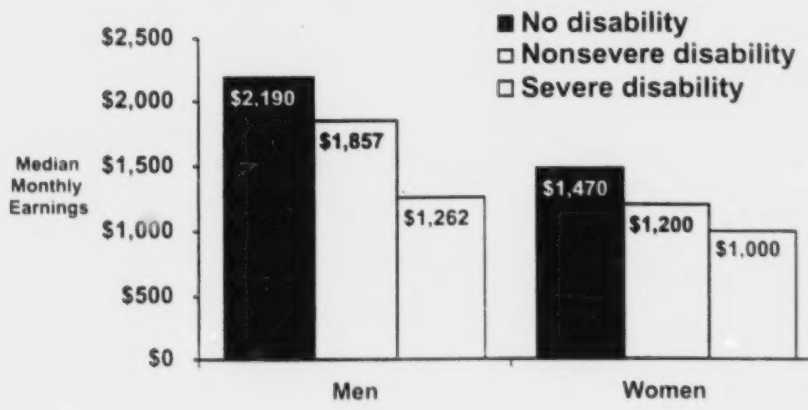
An employee with visual impairments uses a Braille typewriter in her work as an information and referral specialist.

Figure 1: Labor Force Participation of People Ages 16 to 64 in Fiscal Year 1996



Note: Data are from the U.S. Census Bureau, March 1998, Current Population Survey.

Figure 2: Monthly Earnings of Working People By Disability Status



Note: Data are from the 1994-95 SIPP Survey, as reported by McNeil in 1997 and interpreted in Stoddard, Jans, Ripple, and Kraus, 1998.

Even when people with disabilities are employed full-time, their earnings are substantially lower than those of people without disabilities. The severity of disability also correlates inversely with the level of earnings. Disparities in employment rates and earnings are even greater for disabled individuals from minority backgrounds and those with the most significant disabilities (Stoddard, Jans, Ripple, & Kraus 1998).

Economy and Labor Force Issues

Several emerging characteristics of the nation's labor market exacerbate the difficulties that people with disabilities experience in their attempts to gain employment and even in their motivation to seek employment. Downsizing, for example, has led to a lower percentage of people with stable, long-term jobs with benefits. Many businesses and industries are moving to other configurations that fill their labor needs without requiring a long-term commitment on the part of the employer. The contingent workforce takes many forms, including on-call workers and those in temporary help agencies, workers provided by contract firms, and independent contractors who receive their wages or salaries directly from the company. Many of these jobs lack security and benefits, particularly health insurance, which most people with disabilities require to participate in the labor force.

In addition, many business spokespeople and educators point to the need for highly educated, highly skilled workers if the nation is to succeed in an increasingly competitive global economy. The reality, however, is more complex. On the one hand, the availability of jobs requiring specialized skills combined with rapid advances in technology may improve the employment prospects of people with disabilities as well as other workers, through such work arrangements as telecommuting and an expanding market for self-employment or small businesses. On the other hand, the labor market appears to be moving toward increasing bifurcation, with top-tier technocracy jobs for people with sophisticated work skills and lower-tier unskilled service and maintenance jobs for the less-prepared.

Assisting individuals with significant disabilities in moving from dependency on public benefits or family support, or from episodic, poor-paying jobs into stable jobs that will allow them to become self-supporting, is a complex challenge. This challenge involves a number of economic sectors, and service and support systems, and must include an examination of social policies. Providing appropriate assistance requires an extensive knowledge base encompassing economic trends, education and job training strategies, job development and placement techniques, workplace

supports and accommodations, and empirical knowledge of the impact of social and health insurance policies on job-seeking behaviors.

State-Federal Vocational Rehabilitation Program

For the past 75 years, the primary source of publicly funded employment-related services to improve the employment status of disabled people—especially those with significant disabilities—has been the State-Federal Vocational Rehabilitation (VR) service program.

The program is currently authorized under the Rehabilitation Act of 1973, as amended, most recently in 1998. Funded at $2.2 billion in fiscal year 1998 in federal funds with a 22 percent state match for a total of about $2.7 billion, the program is implemented primarily as a case management system at the state and local levels. The rehabilitation counselors negotiate, on behalf of and in consultation with the consumer, the purchase of a package of services, such as medical interventions and support services (e.g., training, assistive technology, and help obtaining the appropriate tools) that will enable the consumer to find and keep a job.

In 1997, OSERS Assistant Secretary Judith Heumann testified before Congress on "Barriers Preventing Social Security Recipients from Returning to Work." She noted, "As a group, people who achieve an employment outcome as a result of vocational rehabilitation services each year show notable gains in their economic status." The percentage of people with disabilities who reported their earnings as their primary source of support increased from 18 percent at the time they applied to the VR program to 82 percent at the time they left the program (Heumann 1997). The percentage with earned income of any kind increased from 22 percent at entry to 92 percent at exit. The percentage working at or above minimum wage rose from 15 percent to 80 percent.

Nevertheless, federal policy-makers, consumers, advocates, and rehabilitation professionals remain concerned that people with disabilities often are excluded from full participation in the nation's labor force. In the past several years, for example, SSA has experienced a very large increase in the number of people qualifying for SSI and SSDI. In addition, the public costs of these cash benefits are substantially increased by the addition of public support for associated Medicare and Medicaid programs. Further, neither SSA nor the VR system has experienced notable success in returning beneficiaries to the labor force. The VR system, while accepting SSI and SSDI beneficiaries for services at a proportionally higher rate than nonbeneficiaries, typically has less success with this group; that is, relatively fewer SSI and SSDI beneficiaries than

nonbeneficiaries achieve employment outcomes as a result of VR services.

One of the major changes in the employment sector over the past three decades is the diversification of the labor force. Workers with disabilities are among the previously underrepresented groups entering the labor market in increasing numbers with raised expectations and legal protections for equal opportunity in employment. Even within the disability community, there is great diversity in the subgroups that have obtained or desire employment. It is very important that future research and service programs demonstrate in their design and implementation appropriate sensitivity to and adequate representation of the range of cultural and disability subgroups.

This issue should be examined not merely as a response to the current consciousness about multiculturalism, but also because the basic, implicit foundations of vocational rehabilitation counseling were developed for people who, in terms of demographic characteristics, work-related experience, and service needs, were quite different from today's rehabilitation customers. Specifically, vocational rehabilitation techniques were originally imported from the earlier established disciplines of secondary vocational education and college counseling psychology. Recipients of services from these disciplines tended to have mainstream acculturation and tolerance for the competitive standards, verbal testing, and guidance common in academic environments. Given the cognitively compromised or socially disadvantaged status of many of today's clients, additional scrutiny of the appropriateness and adequacy of the strategies and tools for vocational rehabilitation assessment, counseling, and training is imperative. Rehabilitation counselors need new marketing strategies to reach out to prospective employers to develop job opportunities for this diverse population of people with disabilities.

Community-Based Employment Services

NIDRR's research agenda concerning employment addresses, but is not limited to, the State-Federal VR program, administered by NIDRR's sister agency, the Rehabilitation Services Administration (RSA). While the VR program plays an important role, there is a wide range of other federal, state, and local funding sources for, and providers of, employment programs. These include approximately 7,000 community-based rehabilitation programs (CRPs), which serve about 800,000 people daily, and are funded by VR and/or such diverse sources as the Job Training Partnership Act (JTPA), worker's compensation, or private

insurance. Legislation such as the Workforce Investment Act and the Workforce Consolidation Act further diversifies the sources of support.

The role of community rehabilitation programs in the overall service delivery system may be enhanced even further if federal employment programs devolve to states and communities and if the intent to increase consumer choice in selecting service providers becomes more widely implemented. To respond to these developments, community rehabilitation programs must prepare to offer a full range of vocational services to an increasingly heterogeneous consumer population. Moreover, as return-to-work programs that base provider payments on successful consumer outcomes are implemented, new relationships between service providers and funding sources may emerge over the next few years. These new relationships will require that community rehabilitation programs adapt their current structure and operations in significant ways.

There are still a number of questions about how these changes may potentially influence the delivery of community rehabilitation services. For instance, the efficacy of different models designed to maximize competitive employment outcomes for people with significant disabilities or with specific types of disabilities is unknown. In addition, the impact of consumer choice on service delivery models is unknown. Finally, whether new funding mechanisms will promote increased competition and innovation in service delivery by community rehabilitation programs is a major question. Gaining knowledge in these important areas will allow validation of the assumptions upon which pending reforms are predicated. This knowledge may also shape the future direction of initiatives to enable more people with significant disabilities to obtain and retain meaningful employment.

Employer Roles and Workplace Supports

Employers play a key role in deciding employment outcomes for disabled people by establishing policies for recruitment, screening, hiring, training, promoting, accommodating, and retaining disabled individuals in the workforce. The provisions of Title I of the ADA prohibit discrimination against qualified job applicants with disabilities. Applicants are considered qualified if they can perform the essential functions of a job with or without reasonable accommodations. This statute creates duties for employers by requiring them to make the employment process accessible, provide reasonable accommodations, and focus on essential functions of jobs. These employer responsibilities cover all aspects of the pre-employment and post-employment phases. Through the requirements of

workers' compensation laws, bargaining unit agreements, and insurance provisions, employers have additional obligations to employees who become disabled.

Strategies to assist employers in meeting workplace obligations include disability management and workplace supports. Disability management is a term used to describe an array of support mechanisms and benefits that employers use to maintain employment for disabled workers.

Workplace supports are programs or interventions provided in the workplace to enable people with disabilities to be successful in securing and maintaining employment. Accommodations such as job restructuring, worksite adaptations, and improved accessibility are examples. Supported employment is a specific approach to improve employment outcomes for some people with disabilities, usually involving a job coach employed by a rehabilitation service provider to provide on-the-job assistance.

Technology can play a major role in making workplaces accessible and in enabling individuals with disabilities to complete work tasks by adapting tools and processes. Ergonomics, universal design, and assistive technology devices are all strategies to enhance workplace performance.

Transition from School to Work

NIDRR, along with RSA, OSEP, and the entire Department of Education, is particularly interested in the process by which disabled students make the transistion to productive work, rather than settle into a lifetime of dependency. This is a critical concern because the transition period presents a distinct opportunity to help students embark on a career, thus enhancing their community integration, independence, and quality of life. The transition into work occurs at many points: prevocational experiences, on-the-job training, secondary vocational education and other secondary education programs, along with postsecondary education at technical institutions, community colleges, or universities. These various transition points present opportunities for research on strategies for success in transferring from a learning environment to a work environment.

Research is ongoing regarding issues of postsecondary education for people with disabilities. This research shows that youth with disabilities face tremendous difficulties in accessing postsecondary education and making the transition from school to work. Most of the nation's institutions of higher education offer support services to students with disabilities; however, this support is less certain for other types of

postsecondary schools. When offered, services vary widely and may include customized academic accommodation, adaptive equipment, case management and coordination, advocacy, and counseling. A number of issues have been raised concerning the delivery of these services. Among these are issues of disclosure, accessibility of a range of services, and the extent and type of transition services needed to move from school to work.

Directions of Future Employment-Related Research

Given the magnitude of changes in the nature and structure of the world of work and possible changes in the characteristics of the disabled population, NIDRR's employment-related research agenda for the next five years must extend beyond prior research efforts to discover mechanisms that will make the labor market more amenable to full employment for people with disabilities. That research agenda must incorporate economic research, service delivery research, and policy research.

Most important, NIDRR's research must relate to the context in which employment outcomes are determined. Among the key policy issues that will affect the evolution of this agenda are SSA reform; restructured funding and payment mechanisms, including the use of vouchers; the impact of workforce consolidation; radical restructuring of employment training services at state and local levels; employment-related needs of unserved and underserved groups; linkage of health insurance benefits to either jobs or benefit programs; and transition from school to work among youth with disabilities.

An important focus for research will be changes in the environment (e.g., the workplace, information technology, telecommunications, and transportation systems) that will make work more accessible, along with strategies for assisting individuals to achieve both the skill levels and the flexibility required for full labor force participation in the 21st century. Finally, as a departure from NIDRR's historical emphasis on the service system and the quality of services, the agenda calls for examination of economic issues (e.g., benefits and costs of various incentive plans) associated with employment of people with disabilities, labor force projections and analyses, and an increased understanding of employer roles, perspectives, and motivational systems.

The purposes of NIDRR's research in employment are to:

- assess the impact of economic policy and labor market trends on the employment outcomes of people with disabilities;

- improve the effectiveness of community-based employment service programs;

- improve the effectiveness of state employment service systems;

- evaluate the contribution of employer practices and workplace supports to the employment outcomes of people with disabilities; and

- improve school-to-work transition outcomes.

Future Research Priorities for Employment

Economic Policy and Labor Market Trends. As noted earlier in this chapter, NIDRR recognizes that the impact of macroeconomic trends on employment of people with disabilities, and public policy responses to these trends, is a large and complex topic, one that will require increased policy research attention in the next 5 to 10 years.

A coordinated research effort must examine such labor market demand issues as the changing structure of the workforce, skill requirements, and recruitment channels, in addition to issues on the supply side such as job preparation and skills, competencies, demographics, and incentives and disincentives to work. Specific research priorities include:

- an analysis of the implications for employment outcomes of cross-agency and multiagency developments and initiatives, including welfare reform, workforce consolidation, SSA reform, Medicare and Medicaid changes, the Department of Education-Department of Labor school-to-work program, and Executive Order No. 13078 (1998);

- an analysis of the dissonance between the ADA concept of *essential elements* of a job and the new employer emphasis on core competencies, flexibility, and work teams, and the impact of these differences on job acquisition and retention; and

- an analysis of the impact of labor market changes on employment of people with disabilities, including alternative employment arrangements such as small business entrepreneurship, self-employment, telecommuting, part-time work, and contractual work.

Community-Based Employment Service Programs. Proposed restructuring of the financing of employment-related services for individuals with disabilities posits a major role for new or different service delivery arrangements. The capacity of the existing provider system, represented in part by the 7,000 community-based rehabilitation programs (CRPs) in

the nation, to assume this role requires thorough investigation.

Specific research priorities include:

- an evaluation of provisions for accountability and control, and protections for difficult-to-serve individuals; an analysis of the costs and benefits of services; and a measurement of the quality of employment outcomes for consumers with disabilities;

- an analysis of the extent to which the services that CRPs deliver to VR consumers (about one-third of services received by VR consumers come from CRPs) differ in quality, quantity, costs, or outcomes from those provided to consumers of other financing systems (e.g., workers' compensation or private insurance); and

- an evaluation of the potential of this community-based employment system to assume greater responsibility for service delivery under block grants, in consolidation into umbrella agencies, and in *one-stop shop* service configurations.

State Service Systems. Amendments to the Rehabilitation Act in 1992 and 1998 called for a number of management and service delivery changes in the State-Federal VR program. These include expanded consumer choices regarding vocational goals, services, and service providers; the implementation of performance standards and accountability indicators to ensure improvement in the system; a greater role for consumer direction through State Rehabilitation Advisory Councils (RACs); and changes in the eligibility determination process that include presumptive eligibility and the order of selection procedures, among others.

The order of selection requires that individuals with the most significant disabilities receive priority for services, significantly altering the characteristics of VR clientele.

Specific research priorities include the following:

- an analysis of the impact of management and service delivery changes in the State-Federal VR program on the quality and outcomes of VR services;

- an evaluation of the impact of professionalization of the rehabilitation counselor workforce;

- an assessment of the efficacy of various methods of case management;

- the development and evaluation of outcomes measures for VR consumers under one-stop configurations;

- the identification and evaluation of marketing strategies to assist VR counselors in helping people with disabilities obtain jobs in a variety of employer settings;

- an assessment of interagency coordination in delivering services to multiagency consumers;

- an assessment of the outcomes of small business entrepreneurship and self-employment as strategies to improve outcomes for vocational rehabilitation clients; and

- an assessment of the applicability of traditional VR approaches for minority and emerging universe populations.

Employer and Workplace Issues. One area that has received insufficient research is the workplace, including both the physical environment (e.g., job site accommodations, technological aids, and the like) and the social environment, comprising roles of co-workers, supervisors, and employers.

Specific research priorities include:

- the investigation of employers' hiring and promotion practices;

- an evaluation of models of collaboration between rehabilitation professionals and employers;

- the development and evaluation of cost-effective strategies for improving the receptivity of the workplace environment to workers with disabilities;

- the development and evaluation of strategies for encouraging employers to hire disabled workers (e.g., tax credits, arrangements regarding partial support for medical benefits);

- an evaluation of the impact of new structures of work, including telecommuting, flexible hours, and self-employment on employment outcomes;

- the identification and evaluation of disability management practices by which employers can assist workers who acquire or aggravate disabilities to remain employed, transfer employment, or remain in the workforce and out of public benefits programs; and

- an analysis of the role and potential of the ADA in increasing job opportunities.

School-to-Work Transition. Moving into employment from educational institutions is one of the most important transitions that people make during their lifetimes. The academic levels at which transitions to the labor market occur include during secondary school, at secondary school completion, and at

completion of some level of post-secondary education. In recent years, the U.S. Departments of Education and Labor have collaborated to support the development of state and local systems whose broad mission is to prepare youth for success in the global marketplace.

Specific research priorities include:

- the determination of the impact of these state and local educational system initiatives on work opportunities for the nation's youth with disabilities;

- the evaluation of whether school reform initiatives—such as academic-vocational integration, Tech Prep, career academies, work-based learning, and rigorous preparation in terms of critical thinking and communication skills—are accessible to and effective with youth who have disabilities;

- the identification of systemic and environmental barriers to full labor force participation;

- an assessment of whether inovations in school-to-work practices are accessible to youth with disabilities and determination of the impact of these practices on employment outcomes; and

- an assessment of the efficacy of employment and transition services for youth from diverse backgrounds and new disability groups.

Future employment research will provide information to develop new VR approaches for helping disabled individuals become competitive in the changing, global labor market. These new methods will focus on provision of culturally relevant services for clients, attainment of competitive job skills by clients, and the application of accommodations in the workplace.

Chapter 4

HEALTH AND FUNCTION

To be healthy does not mean to be free of disease; it means that you can function, do what you want to do, and become what you want to become.

—Rene Jules Dubos
1901 - 1982

Overview

Maximizing health and function is critical to maintaining independence for people with disabilities. Health care for people with disabilities encompasses access to care for routine health problems, participation in health promotion and wellness activities, and access to appropriate specialty care, including medical rehabilitation. Medical rehabilitation is the systematic application of modalities, therapies, and techniques to restore, improve, or replace impaired human functioning. It also encompasses biomedical engineering, that is, the use of engineering principles and techniques and biological knowledge to advance the functional ability of people with disabilities.

Health care and medical rehabilitation services operate largely within the constraints imposed by market forces and government regulations. In recent years, significant changes have occurred in health care delivery and reimbursement. Various forms of managed care have become the predominant mode of organizing and delivering health care in much of the private sector. Medicaid and Medicare also have adopted managed care strategies for providing health care to many recipients. In theory, managed care uses case coordination to contain costs by limiting access to what the managed care company considers unnecessary health care, particularly specialty services and hospitalization. Individuals with disabilities have expressed concern that managed care approaches may limit their access to medical rehabilitation specialists, goods, and services. In addition to a market-driven shift to

"We'll have no reason to congratulate ourselves until the day when we assume that every disabled person has the right to rehabilitation, just as we now assume that everyone with a broken arm must have it set and splinted. Before that day arrives, many thousands of young people in the health field must become dedicated to rehabilitation and choose it as a career."

—Howard A. Rusk, M.D.
A World to Care For: The Autobiography of Howard A. Rusk, M.D.

managed care, other related changes have occurred, including shortened periods of stay in inpatient rehabilitation facilities and the emergence of subacute rehabilitation providers. Considerable consolidation also has occurred within the medical rehabilitation industry and has further affected the availability and delivery of services. There is a new emphasis on developing performance measures that incorporate quality, functional outcomes, and consumer satisfaction. These measures are being used to guide purchasing and accrediting decisions within the health care system.

During the next five years, NIDRR plans to fund research in a number of broad areas that link health status and functional outcomes to health care and medical rehabilitation. In addition, NIDRR will support research to continue development of new treatments and delivery mechanisms to meet the rehabilitation, functional restoration, and health maintenance needs of individuals with disabilities. This research will occur at the individual and the delivery system levels. In this section, the discussion of general health care and medical rehabilitation will address issues at both levels.

Health Care

The goal of health care for individuals with disabilities is attaining and maintaining health and decreasing the occurrence of secondary conditions of disability. Individuals with disabilities use more health care services, accumulate more hospital days, and incur higher per capita medical expenditures than do nondisabled people. People with no activity limitations reported approximately four physician contacts per year; this figure doubled for those who had some activity limitation, five times as high for those unable to perform major life activities, and seven times as great for those needing help with instrumental activities of daily living (LaPlante 1993). Understanding the relationship between disability and health has implications for the public health agenda and the application of primary disease prevention strategies to the health of people with disabilities.

In the past, the health needs of people with disabilities often have been conflated with medical rehabilitation needs. The recognition that people with disabilities require routine health care or access to health maintenance and wellness services is relatively new. How best to meet these needs requires substantial new research. At the individual level, people with disabilities need providers and interventions that focus on their overall health, taking disability and environmental factors into consideration. Concern about the health of the whole person is the focus at this level, in recognition that an individual is more than a disability and deserves access to the

health services generally available to the nondisabled population. At the systems level, the study of the organization and financing of health services must include an analysis of the impacts on people with disabilities. Ameliorating the primary condition, preventing secondary conditions and co-morbidities, maximizing independence and community integration, and examining the impact of physical barriers and societal attitudes on access to health and medical rehabilitation services are critical issues at each level of focus.

Health Care at the Individual Level

Although people with disabilities have higher health care utilization rates than the general population, having a disability does not mean that a person is ill. People with disabilities increasingly are demanding information about and access to programs and services aimed at promoting their overall health, including access to routine health care, preventive care, and wellness activities. This includes primary care and, for women, access to gynecological care. For children, this means access to appropriate pediatric care. In clinical settings, these demands require development of disability-sensitive protocols for proper nutrition, exercise, health screening, and treatment of nondisability-related illnesses and conditions. NIDRR is committed to supporting research to improve the overall health of people with disabilities.

Health Care at the Systems Level

People with disabilities must have access to, and be satisfied with, an integrated continuum of health care services, including primary care and health maintenance services, specialty care, medical rehabilitation, long-term care, and health promotion programs. Models for organizing, delivering, and financing these services must accommodate an overall health care system that is undergoing tremendous change. Issues of gatekeeper roles, carve-outs, risk-adjusted rate-setting, and service mix are factors for assessment in a context of managed care approaches that balance care coordination with cost control strategies. At issue for all people is whether cost control strategies result in barriers to needed care, and for people with disabilities, whether access to specialty care, particularly medical rehabilitation services, is limited. In the current cost-cutting and restrictive climate, it is important that new service configurations preserve equity for people with disabilities by providing for their unique needs.

Medical Rehabilitation

Medical rehabilitation addresses both the primary disability and secondary conditions evolving from the initial impairment or disability. Medical

rehabilitation also teaches the individual to overcome barriers in the environment. Medical rehabilitation includes medical and bioengineering interventions, therapeutic modalities, and community and family interventions.

Medical rehabilitation frequently is associated with physical disabilities such as musculoskeletal or neuromuscular impairments or limitations in mobility or manipulation. However, medical rehabilitation also provides interventions to improve or manage sensory, cognitive, and mental health functioning, pain, or fatigue, and includes rehabilitation dentistry and maxillofacial prosthodontics. Specialists and allied health personnel from a broad range of disciplines may be involved in the provision of medical rehabilitation services.

Medical Rehabilitation at the Individual Level

NIDRR-funded research has improved medical rehabilitation treatment in areas such as spinal cord injury, traumatic brain injury, stroke, and other leading causes of disability. NIDRR will expand this research to include emerging disabilities. Of special concern are new causes of disability such as violence, which has emerged in recent years as a significant precipitator for new disability conditions. In addition, future medical rehabilitation research must be sensitive to cultural differences and must recognize the impact of an individual's environment on functional outcomes. Another important research focus will be examining how technological improvements enhance the ability of biomedical engineering to help people with disabilities regain, maintain, or replace functional ability.

Additionally, an urgent need exists for the development of more effective outcomes measurement tools to test the usefulness of new medical rehabilitation interventions and products. These measurement tools must assess the individual's response to medical rehabilitation interventions and account for technology that enhances mobility, independence, and quality of life. Outcomes must be measured not just for the duration of treatment but also over the long-term.

The prevention and treatment of secondary conditions are a significant challenge to the medical rehabilitation field. Secondary conditions result directly from the primary disabling condition and may have significant effects on the health and function of people with disabilities. Examples of secondary conditions may include depression, bladder and skin problems, respiratory problems, chronic pain, contractures or spasticity, fatigue, joint deterioration, or memory loss. Other health conditions such as

cardiac problems, autoimmune diseases, obesity, or cancer may not always derive directly from the original disability, but may require special preventive efforts or care interventions because of a preexisting disability.

Medical Rehabilitation at the Systems Level

Cost containment strategies inherent in managed care may limit access to medical rehabilitation. Thus, it is more important than ever to demonstrate the cost effectiveness of treatments. Research on medical rehabilitation outcomes is critical to establishing the need for, and assuring access to, medical rehabilitation within the health care delivery system.

NIDRR has initiated research activities to develop methods for measuring function and assessing rehabilitation outcomes, and for measuring the cost and effectiveness of various rehabilitation modalities and delivery mechanisms. These areas will continue to be important foci of NIDRR's future medical research program. Researchers must continue to assess the impact of changes at the systems level on the rehabilitation outcomes of individuals. In addition, providing care in nonacute settings requires developing additional capacity, such as training practitioners for more independent work in the community. NIDRR research must contribute to building this new capacity.

The purposes of NIDRR's research in the area of health care and medical rehabilitation are to:

- identify and evaluate effective models of health care for people with disabilities;
- develop models to promote health and wellness for people with disabilities;
- examine the impact of changes in the health care delivery system on access to care;
- evaluate medical rehabilitation interventions that maximize physical, cognitive, sensory, and emotional functioning for individuals with disabilities, taking into account aging, environment, emerging disabilities, and changes in the health services delivery system;
- identify and evaluate medical rehabilitation interventions that will help disabled individuals maintain health, through prevention and amelioration of secondary conditions and co-morbidities and through education;
- improve delivery of medical rehabilitation services to people with disabilities; and

- evaluate the health and medical rehabilitation needs of people whose impairments are attributed to newly recognized causes or whose conditions are becoming recognized as disabilities. Examples include a disability resulting from interpersonal violence and emergent chronic diseases such as childhood asthma or chronic fatigue immune deficiency syndrome.

Future Research Priorities For Health Care and Medical Rehabilitation

Research on Effective Methods of Providing a Continuum of Care, Including Primary Care and Long-Term Care, to People with Disabilities. In recent years, a number of different models of providing routine health care for people with disabilities have emerged. For example, medical rehabilitation programs have developed primary care clinics; and there are other programs where primary care providers have added medical rehabilitation consultants to advise them on the care of people with disabilities. The efficacy of these models is not yet known, especially their impact on the overall well-being of consumers.

There has been some research on long-term care models, especially those that provide community-based services, including personal assistance; however, research questions remain regarding optimal models of long-term care. Specific priorities include:

- identification of effective models of primary and long-term care across disability populations including emerging disability groups;

- evaluation of the impact of primary and long-term care service delivery models on independence, community integration, and overall health outcomes, including occurrence of secondary conditions and co-morbidities; and

- collection and analysis of longitudinal data on health care utilization by people with disabilities to identify trends, outcomes, and consumer satisfaction.

Research on Application of Wellness and Health Promotion Strategies. NIDRR will support research to develop wellness and health promotion strategies, incorporating all disability types and all age groups. Specific research priorities include:

- identification and evaluation of models to promote health and wellness for people with disabilities in mainstream settings where possible. These include nutrition, exercise, disease prevention, and other health promotion strategies.

NIDRR will place a particular focus on prevention and treatment of secondary conditions, such as pressure sores, and on the needs of emerging disability populations, including people aging with a disability;

- evaluation of the impact of health status on independence, community integration, quality of life, and health care expenditures; and

- development of guidelines that establish protocols for reaching or maintaining appropriate levels of fitness for people with varying functional abilities.

Research on the Impact of the Evolving Health Service Delivery System on Access to Health and Medical Rehabilitation Services. NIDRR anticipates that the health service delivery system will continue to evolve as the marketplace responds to rising costs and as policy-makers respond to public concerns about access to care. Specific research priorities include:

- evaluation of the impact of changes at the health system level (e.g., financing and regulatory changes) and on access to the continuum of health care services (e.g., medical rehabilitation); and

- evaluation of the impact of triage and case management strategies on health status and rehabilitation outcomes.

Research on Trauma Rehabilitation. Research to improve the restoration and successful community living of individuals with burns and neurotrauma, such as spinal cord injury, brain injury, and stroke, has long been an important component of NIDRR's program. Specific research priorities include:

- identification of methods to minimize neurological damage, improve behavioral outcomes, and enhance cognitive abilities; and

- identification of effective collaborative research opportunities, including those using data generated by the model systems.

Research on Progressive and Degenerative Disease Rehabilitation. Research to maintain and restore function and independent lifestyles for individuals with multiple sclerosis, arthritis, and a neuromuscular disease is a key element of medical rehabilitation research. Specific research priorities include:

- identification and evaluation of methods to maintain function for people with these conditions;

- identification of effective health promotion strategies;
- evaluation of strategies to minimize the impact of secondary conditions; and
- development and evaluation of health care and rehabilitation medicine supports to facilitate community integration and independent living outcomes.

Research on Birth Anomalies and Sequelae of Diseases and Injuries. Medical and technological interventions to maintain and restore function in people with cerebral palsy, spina bifida, post-polio syndrome, and other long-standing conditions are an important part of rehabilitation. Specific research priorities include:

- development and evaluation of physical therapy techniques, respiratory management techniques, exercise regimens, and other rehabilitative interventions aimed at maximizing functional independence;
- development and evaluation of supports to facilitate community integration and independent living outcomes; and
- investigation of factors that lead to disability and loss of full participation in society following disease or injury.

Research on Secondary Conditions. Preventing and treating secondary conditions are critical to preserving health and containing the health care costs of people with disabilities. Specific research priorities include:

- development of clinical guidelines to identify at-risk individuals and to involve consumers in regimens to prevent secondary conditions;
- identification and evaluation of methods of preventing and treating secondary conditions across impairment categories; and
- investigation of the interaction among secondary conditions, impairments, and aging.

Research on Emergent Disabilities. Explorations of the impact of disabilities resulting from new causes or expanded disability definitions will be increasingly significant to rehabilitation medicine. Emergent conditions may include such things as environmental illnesses, repetitive motion syndromes, autoimmune deficiencies, and psychosocial and behavioral conditions related to poverty and violence. Specific research priorities include:

- identification and evaluation of the need for health and medical rehabilitation services to address emerging disability conditions;

- identification and evaluation of effective models that health and medical rehabilitation providers can use to meet the needs of people with emerging disabilities; and

- development of models to predict future emerging disability populations.

Research on Aging with a Disability. Advances in acute medical care for people with disabilities means that, as the population ages, many disabled people will live longer and may develop the serious, chronic conditions common to many aging populations. Examples of such conditions include heart disease, diabetes, cancer, pulmonary diseases, arthritis, and sensory losses. Specific research priorities include:

- determination of the implications of aging with a disability on access to routine health care, medical rehabilitation services, and services that support community integration;

- investigation of the impact of aging on disabilities and of disabilities on aging;

- investigation of the relationship between age-related disability and employment; and

- analysis of the effect of a longer lifespan on the durability and effectiveness of previously demonstrated interventions and technologies.

Research on Rehabilitation Outcomes. NIDRR's prior research efforts have developed new rehabilitation techniques for a number of disability groupings and also have developed and tested comprehensive model systems, home and community-based services, and peer services to improve rehabilitation outcomes. With the renewed emphasis on performance and outcomes and with increasing economic constraints generated by changes in the health services delivery system, rehabilitation medicine needs to document the impact of its services. Specific research priorities include:

- expansion of outcomes evaluation approaches, beyond short-term rehabilitation studies, to include outpatient and long-term follow-up information;

- development of outcomes measures that include measures of environmental barriers;

- evaluation of methods that translate outcomes findings into quality improvement strategies;

- analysis of barriers and incentives to consistent use of health and medical rehabilitation outcomes measures in payer-driven and consumer choice service models; and

- refinement of measures of rehabilitation effectiveness.

Research on Changes in the Medical Rehabilitation Industry. The medical rehabilitation industry is undergoing an unprecedented level of consolidation, with unknown consequences for access and flexibility. The industry has undergone significant changes in service sites with the move from inpatient to post-acute, outpatient, and community-based services. Outcomes measurement and quality assurance initiatives are increasingly used in evaluating medical rehabilitation services. Specific research priorities include:

- investigation of the impact of financing and other market forces on the medical rehabilitation industry, including service delivery patterns and treatment modalities; and

- identification and evaluation of the impact of changes at the medical rehabilitation industry level on access and outcomes for people with disabilities.

A major research challenge will be to integrate research on the efficacy of interventions to improve outcomes with research on the impact of changes in the health care delivery system. A second overarching objective will be to relate medical rehabilitation and health care research to other changes, including the new paradigm of disability, the emerging universe of disability, and participatory research by people with disabilities.

Chapter 5

TECHNOLOGY FOR ACCESS AND FUNCTION

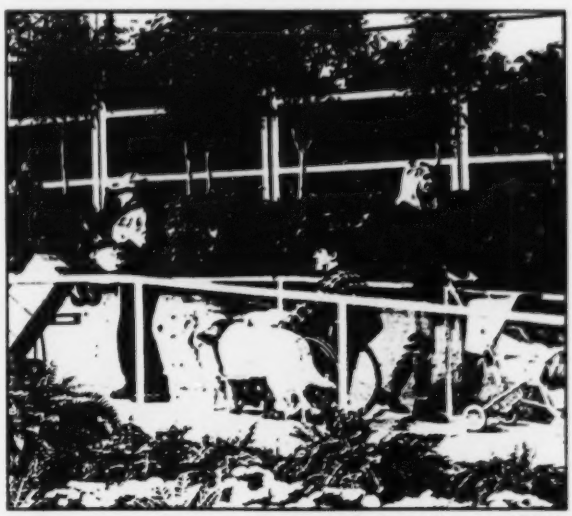
For Americans without disabilities, technology makes things easier. For Americans with disabilities, technology makes things possible.

—Mary Pat Radabaugh
"Study on the Financing of Assistive Technology Devices of Services for Individuals with Disabilities"

Overview

Technology has been defined as the system by which a society provides its members with developments from science that have practical use in everyday life. Today, technology plays a vital role in the lives of millions of disabled and older Americans. Each day, people with significant disabilities use the products of two generations of research in rehabilitation and biomedical engineering to achieve and maintain maximum physical function, to live in their own homes, to study and learn, to attain gainful employment, and to participate in and contribute to society in meaningful and resourceful ways. It is more than a coincidence that these remarkable advances have occurred during the period in which federal funds have supported research, development, and training in rehabilitation engineering.

In planning the future of rehabilitation engineering research, NIDRR and its constituents in the consumer, service, research, and business communities will continue to identify flexible strategies to address emerging issues and technologies, to promote widespread use of research findings, and to maximize the impact of NIDRR programs on the lives of people with disabilities. NIDRR is particularly well-positioned to continue its leadership in rehabilitation engineering research, since NIDRR



Courtesy of The Rocky Mountain DBTAC

Ramps are one example of accommodations that can provide all people with equal access.

locates rehabilitation engineering research on a continuum that includes related medical, clinical, and public policy research; vocational rehabilitation and independent living research; research training programs; service delivery infrastructure projects; and extensive consumer participation.

The institute supports engineering research on technology for individuals and on systems technology. For example, NIDRR has supported hearing aid and wheelchair research on the individual level, and telecommunications, transportation, and built environment research at the systems or public technology level. NIDRR also supports research on ergonomics and interface problems related to the compatibility of various technologies, such as hearing aids and cellular telephones.

Technological innovations benefit disabled people at the individual level and at the systems level. At the individual level, assistive technology enhances function; at the systems (or public technology) level, technology provides access that enhances community integration and equal opportunity. Most assistive technology for disabled individuals falls into the category of *orphan* technology because of limited markets; frequently this technology is developed, produced, and distributed by small businesses. Often, technology on the systems level involves large markets and large businesses. Access to technology can be increased by incorporating principles of universal design into the built environment, information technology and telecommunications, consumer products, and transportation.

Assistive Technology For Individuals

In 1990, more than 13.1 million Americans, about 5 percent of the population, were using assistive technology devices to accommodate physical impairments, and 7.1 million people, nearly 3 percent of the population, were living in homes specially adapted to accommodate impairments. While the majority of people who use assistive technology are elderly, children and young adults use a significant proportion of the devices, such as foot braces, artificial arms or hands, adapted typewriters or computers, and leg braces (LaPlante, Hendershot, & Moss 1992).

Assistive technology includes devices that are technologically complex, involving sophisticated materials and requiring precise operations—often referred to as *high-tech*—and those that are simple, inexpensive, and made from easily available materials—commonly referred to as *low-tech*. Scientific research in both high-tech and low-tech areas will serve the consumer need for practical items that are readily available and easily used. Low-tech devices, for example, are

widely used by older people with disabilities to compensate for age-related functional losses. The importance of creating both types of assistive technologies is found in the words of one engineer, who stated, "It is not high-tech or low-tech that is the issue; it is the right tech." NIDRR research must be able to identify the most appropriate technological approach for a given application, and continue to develop low-tech as well as high-tech solutions.

Given the current trend toward more restrictive utilization of health care funds in both public and private sectors, rehabilitation engineering research must justify consumer or third-party costs in relation to the benefits generated for consumers. These benefits may be in the form of long-term cost savings and consumer satisfaction. Equally important, rehabilitation engineers must develop products that are, in addition to being safe and durable, marketable and affordable. End-product affordability is important, not only in meeting consumer needs, but also in creating the market demand that will encourage manufacturers to enter production.

Systems Technology: Universal Design and Accessibility

As disabled people enter the mainstream of society, the range of engineering research has broadened to encompass medical technology, technology for increased function, technology that interfaces between the individual and mainstream technology, and finally, public and systems technology. Key concepts of universal design are: inter-changeability, compatibility of components, modularity, simplification, and accommodation of a broad range of human performance capabilities.

Universal design principles can be applied to the built environment, information technology, and telecommunications, transportation, and consumer products. These technological systems are basic to community integration, education, employment, health, and economic development. The application of universal design principles during the research and development stage would incorporate the widest range of human performance into technological systems. Universal design applications may result in the avoidance of costly retrofitting of systems in use and the possible reduction in the need to develop orphan products.

Technology Transfer

The institute's emphasis on applied research challenges NIDRR and its researchers to find effective ways of ensuring technology transfer—transfer of ideas, designs, prototypes, or products—from the basic to the applied research environment, to the market, and to other research endeavors. Market size, the potential for

manufacturability, intellectual property rights, patents, and regulatory approval are considerations in the conceptualization and design phase of research efforts. NIDRR-funded Rehabilitation Engineering Research Centers (RERCs) consider potential industry partners in selecting research projects that will result in marketable products.

Issues of orphan technology are key to the process of technology transfer, with small markets that have limited capital occasioning the need for subsidies, guaranteed financing for purchases, or other incentives for producers. Future technology transfer efforts at NIDRR will explore better linkages to the Small Business Innovative Research (SBIR) program, a government-wide program intended to support small business innovative research that results in commercial products or services that benefit the public. Innovativeness and probability of commercial success are both important factors in SBIR funding decisions.

Building a Research Agenda

Future rehabilitation engineering research agendas must incorporate several crosscutting issues, including the problem of small markets and the need for reliable outcomes measures. In addition, research must continue to lead to improvements in the functional capacities of individuals with sensory, mobility, manipulation, and cognitive impairments. Telecommunications and computer access offer significant potential to improve participation of people with disabilities in all facets of life. Continuous innovations in these areas require that the needs of people with various disabilities be recognized and accommodated. Finally, access to the built-environment remains a critical need for people with disabilities, and thus requires ongoing research.

The purposes of NIDRR's research in the area of technology are to:

- develop assistive technology that supports people with disabilities to function and live independently and obtain better employment outcomes;
- develop biomedical engineering innovations to improve function for people with disabilities;
- promote the concept and application of universal design;
- remove barriers and improve access in the built environment;
- ensure access of disabled people to telecommunications and information technology, including through the application of universal design principles;
- ensure the transfer of technological developments to

other research sectors, to production, and to the marketplace;

- identify business incentives for manufacturers and distributors;
- identify the best methods of making technology available to people with disabilities;
- ensure that research and development at both the personal and systems levels take into account cultural relevance for diverse ethnic and geographic populations;
- develop rehabilitation engineering science, including a theoretical framework to advance empirical research; and
- raise the visibility of engineering and technological research for people with disabilities as a means of increasing attention to these research areas in national science and technology policy.

Future Research Priorities for Technology

NIDRR's research priorities in engineering and technology will help improve functional outcomes and access to systems technology in sensory function, mobility, manipulation, cognitive function, information communication, and the built environment. The priorities also will promote business involvement and collaboration.

Research to Improve or Substitute for Sensory Functioning. Sensory research is directed toward the problems faced by individuals who have significant visual, hearing, or communication impairments. These major conditions have been the focus of a long tradition of engineering research emphasizing both expressive communication and the receipt of information. Research priorities in the area of sensory functioning will focus on enhancing hearing, addressing visual impairments, and accommodating communication disorders.

In the area of hearing impairments, specific research priorities include:

- development and evaluation of hearing aids that exploit the potential of digital technology and use advanced signal processing techniques to enhance speech intelligibility, attain a better fit, and ensure compatibility with telecommunications systems and information technology;
- evaluation of the application of digital processing techniques to assistive listening systems;
- evaluation of modern methods of sound recognition in alerting devices; and
- development of interfaces for assessment of automatic speech recognition systems.

In the area of visual impairments, specific research priorities include:

- identification and evaluation of methods to enhance accessibility of visual displays;
- development and evaluation of graphical user interface technologies for various document and graphic processing systems; and
- improvement of signage in public facilities.

In the area of communication impairments, specific research priorities include:

- identification and evaluation of technologies to enhance the communication abilities of people who are deaf-blind; and
- assessment of the capacity of research in cognitive science, artificial intelligence, biomechanics, and human and computer interaction to improve the rate, fluency, and use of communication aids.

Research to Enhance Mobility. Mobility research is directed toward the problems associated with moving from place to place. Mobility can be enhanced by accessible public transportation, modified privately owned vehicles, wheeled mobility devices such as wheelchairs, orthoses and prostheses, and barrier removal.

In the area of enhancing mobility, specific research priorities include:

- development, evaluation, and commercialization of wheelchair designs that reduce user stress, repetitive motion injury, and other secondary disabilities, while improving safety, ease of maintenance, and affordability;
- revision and dissemination of wheelchair standards;
- development and evaluation of techniques to assist consumers and providers in selecting and fitting wheelchairs and wheelchair seating systems;
- identification of a theoretical framework of gait and other aspects of ambulation;
- development and evaluation of advanced prosthetic and orthotic devices, as well as footwear and other ambulation devices;
- development and evaluation of methods to improve person-device interfaces, post-surgical management and fitting, and materials used in bio-engineering applications; and
- development of devices to assist with ADLs for people with disabilities and their caregivers.

Research to Improve Manipulation Ability. The manipulation area includes research directed toward

restoring functional independence for people with limited or no use of their hands. This encompasses upper extremity prosthetic and orthotic devices and novel methods of upper extremity rehabilitation. Issues of weight, durability, and reliability remain challenges in this field.

Repetitive motion injury is emerging as one of the most serious problems among workers. Although there have been a number of ergonomic devices introduced to address this problem, the incidence of this condition continues to increase.

In the area of improvement of manipulation, specific research priorities include:

- identification of methods to improve the design of, and achieve multifunctional control for, hand and arm prosthetic technology;
- development and evaluation of surgical approaches that increase functionality;
- development of assistive devices to address manipulation issues for individuals who experience serious weakness, fatigue, or pain, including that attributable to progressive deterioration of function; and
- development and evaluation of devices and techniques to help prevent repetitive motion injuries and to rehabilitate those with the condition.

Research on Technology to Enhance Cognitive Function. Limitations in perception, processing information, organizing thoughts, concentration, memory, and decision-making may result from a range of etiologies—including mental retardation, traumatic brain injury, stroke, mental illness, dementia, and others—and may constitute substantial barriers to function and social integration. These barriers can be exacerbated by sophisticated technology interfaces that require memorizing sequences, reading or interpreting information, or responding to complex auditory or visual cues. Conversely, technology has the theoretical potential to simplify many daily activities and contribute to self-management and independence.

There are three objectives in developing technology to meet the needs of people with limitations in cognitive functioning. The first objective is to assure that new technologies for communication, environmental control, and health maintenance, for example, are accessible to those with cognitive limitations and do not exacerbate their exclusion from mainstream activities.

The second objective is to develop technologies that will assist people with cognitive limitations in the performance of daily activities. Reminders and cueing devices,

trackers and wandering devices, and portable instructional technologies are some of the approaches that enable people with cognitive limitations to remember appointments and medications, locate themselves positionally, follow common instructions, and obtain assistance.

The third objective is to develop technologies that can enhance or restore some cognitive functions. Automated systems to improve memory have been developed and tested, for example. As the fields of cognitive science and neuroscience create a better understanding of the biology of cognitive functioning, and as there are concomitant advances in artificial intelligence and expert systems and in the flexibility of microprocessors, a new research frontier may emerge.

Specific priorities in the area of technology to address cognitive limitations include:

- assessment of state-of-the-art technology and its applications to address cognitive functioning;
- assessment of consumer need and competencies to use various device features;
- development of technologies to improve job skills and to improve employment opportunities;
- development of technologies to maximize independence and the ability to perform ADLs and IADLs; and
- development of strategies to ensure that new technologies for the general population are accessible to people with cognitive limitations.

Research to Improve Accessibility of Telecommunications and Information Technology. Computerized information kiosks, public Web sites, electronic building directories, transportation fare machines, ATMs, and electronic stores are just some current examples of rapidly proliferating systems that face people living in the modern world. To make such computerized information systems usable by people with a range of disabilities, NIDRR's research priorities will include development and evaluation of techniques to assist people with disabilities in successfully accessing these systems.

The trend in the information technology and telecommunications industries is to stay away from standardized operating systems and monolithic applications and move toward net-based systems, applets, and object-oriented structures. This trend has significant implications for accessibility for some people with disabilities. Maintaining access to the Internet and World Wide Web is also a formidable challenge facing individuals with disabilities.

Another concern in telecommunications is electromagnetic interference from the rapidly proliferating wireless communication systems (e.g., beepers, cellular telephones) and other electronic devices using digital circuitry (e.g., computers, fluorescent light controllers). This interference is complicating the use of assistive listening devices. Moreover, the interference caused by the overuse of spectrum is presenting problems in the use of FM assistive listening systems.

During the past decade, virtual reality techniques, originally developed by the National Aeronautics and Space Administration and the military for simulation activities, have been applied in a number of other fields including architecture and health. Applications can be found in telerobotic systems, sign language recognition devices, intelligent home systems, and aids for people with visual impairments. There has been some beginning research on the use of virtual reality as an evaluation and therapy tool.

Telecommunications also emerges in other important areas of the lives of people with disabilities. In a managed care approach to health care, individuals are discharged from acute rehabilitation hospitals earlier than in the past. Because of the decreased lengths of stay, there is less time for consumers to learn how to manage their conditions. One promising option for ameliorating these effects is telemedicine or *telerehabilitation*. Telerehabilitation may allow for distance monitoring of chronic conditions and for monitoring consumer compliance and progress.

In the area of improving accessibility to telecommunications and information technology, specific research priorities include:

- development and evaluation of fine motor skill manipulation interfaces, telecommunication interfaces, and analog to digital communication technologies;
- identification of methods to address issues of accessibility through Internet communications;
- development and evaluation of methods for reducing emerging forms of interference that affect hearing aids, telephones, and other communication devices;
- determination of the efficacy of virtual reality techniques in both rehabilitation medicine and in applications that affect the daily lives of people with disabilities; and
- identification of appropriate telecommunications strategies for use in distance follow-up to rehabilitation treatment.

Research to Improve Access to the Built Environment. The built environment includes public and private buildings, tools and objects of daily use, and roads and vehicles, any of which can be accessible or disabling. Architects, industrial designers, planners, builders, and engineers are among the professionals that create this environment.

In the area of access to the built environment, specific research priorities include:

- analysis of human factors;
- development and evaluation of modular design;
- determination of the best methods of disseminating information on universal design;
- development and evaluation of compatible interfaces; and
- development and promulgation of design standards.

Future engineering research also must recognize the changing roles of consumers, whose participation in research is vital, and the role of assistive technology industries, whose technical capabilities and needs for product development and research are changing. Small businesses, the engine of the orphan technology industry, often cannot support the sophisticated research and development efforts necessary to bring quality products to market.

NIDRR's research can identify public policy issues, such as orphan technology and tax credits, to foster small business investment in assistive technology innovation. Similarly, NIDRR research can identify public policy and business issues related to mainstream systems and public technology. NIDRR will maintain a research capacity that provides a continuing stream of new ideas, and evidence to validate those ideas, to stimulate the industry.

Chapter 6

INDEPENDENT LIVING AND COMMUNITY INTEGRATION

Whether or not we have a disability, we will never fully achieve our goals until we establish a culture that focuses the full force of science and democracy on the systematic empowerment of every person to live to his or her full potential.

—Justin Dart
ON A ROLL RADIO
Internet Web site

Overview

Independent living and community integration concepts and outcomes are key foci of NIDRR research. Central to independent living is the recognition that each individual has a right to independence that comes from exercising control over his or her life, based on an ability and opportunity to make choices in everyday activities. These activities may include participating in community life; fulfilling social roles, such as marriage, parenthood, employment, and citizenship; sustaining self-determination; and minimizing physical or psychological dependence on others.

While independent living emphasizes independence, whatever the setting, by its very nature it is a concept that also promotes participation, especially in community settings. For this reason, NIDRR will integrate its research agenda in independent living and community integration to encourage interdisciplinary thinking about the interrelationship, to achieve more successful outcomes for people with disabilities, and to foster the development of innovative methods to achieve these outcomes and to measure the achievements.

Independent Living and Community Integration Concepts

One framework for formulating this research agenda recognizes that

Leaders of the independent living movement, Justin Dart and Ed Roberts, shared ideas about the movement.

independent living has been used to describe a philosophy, a movement, and a service program. At a philosophical level, independent living addresses the question of equity in the right to participate in society and share in the opportunities, risks, and rewards available to all citizens. It provides a belief system to a generation of people with disabilities. The new paradigm of disability is an outgrowth of this philosophical concept of equity, bringing social and environmental elements to the meaning of disability.

At another level, independent living has been integral to the development of the disability rights movement. This movement primarily has used a civil rights approach to demand equal access for people with disabilities, leading most notably to the passage of the Americans with Disabilities Act (ADA) in 1990. These movement activities have had a significant impact on disability policy and will continue to be examined as part of NIDRR's disability studies funding.

At the service system level, more than 300 centers for independent living receive funding under the Rehabilitation Act and these centers foster and enhance independent living for people with disabilities. In addition, both federal and state funds support community-based residences for members of the developmentally-disabled community as well as members of other disability groups. In the past, NIDRR has supported research to develop management strategies for these centers.

Community integration also has conceptual, movement, and service delivery components. As a concept, it incorporates ideas of both place and participation, in that community integration means not only that a person is physically located in a community as opposed to an institutional setting, but that an individual participates in community activities. Issues of consumer direction and control also are integral to concepts of community integration.

As a movement, community integration had a primary goal of the deinstitutionalization of people with mental retardation or mental illness and has succeeded in moving many individuals from large institutional settings into the community. The deinstitutionalization movement arose from a confluence of consumer advocacy, judicial decisions, research efforts, and public policy reforms. During the last 30 years, deinstitutionalization has decreased the number of individuals with mental retardation and mental illness who live in state institutions by more than 75 percent. In addition, advocacy organizations for people with physical disabilities have implemented the movement aspects of community integration in their

demand for community-based supports and services.

At the service system level, community integration has resulted in development or expansion of a range of services and programs designed to support individuals with disabilities to live in their communities. For instance, individuals who need assistance with activities of daily living (ADLs), such as bathing, dressing, or ambulation, often need personal assistance services (PAS) to live independently in the community. In the traditional service delivery model, long-term care agencies supply PAS by providing home health care aides to individuals. These aides tend to work under the direction of professional health care providers and perform a restricted set of tasks in time frames determined by the agency. A support model, however, shifts the locus of control to the consumer, who is responsible for recruiting, hiring, training, supervising, and firing assistants.

Expanding the Theoretical Framework

NIDRR will continue expanding the knowledge base about the meaning and application of independent living and community integration concepts. This theoretical approach will address issues of inclusion, bases for participation, and ways in which people identify their communities. This effort will be interdisciplinary in nature and will draw from disciplines such as anthropology, sociology, social psychology, history, disability studies, engineering, and medicine.

Each of these disciplines has offered various interpretations of the issues at the core of the concept of community. Anthropologists have defined community to emphasize a shared culture or a way of organizing and giving meaning to life events. Sociologists have discussed community as an organized group dealing with common issues in relation to other organized groups within an environment. Historians have defined community as a web of relationships creating a social order within a political and spatial context that often focuses on issues of who is legitimately a community member.

In the world of disability and rehabilitation, community also has had multiple meanings. In medical rehabilitation, return to community usually refers to life outside a medical facility, typically the community in which an individual resided before an injury or illness. In the disability world, community sometimes means the community of those living with a disability, those who share common experiences.

To go from theory to practice involves identifying the necessary factors for achieving independence within a community setting. In recent years, there has been a shift

from a traditional service delivery model to a model that emphasizes consumer direction and support. As a consequence, individuals with disabilities of all types have shifted from a dependence on agency service providers to an active use of community-based supports. In the support model, consumer choice, customization of needed services, and consumer empowerment are of increased importance compared to the traditional model in which service agencies emphasized professional competence, accountability, and quality control by service providers, and the safety of clients. Also, in the support model, people with disabilities are perceived as self-directed, able, and mainstreamed as opposed to being seen as helpless and objects of care.

Implications for research focus on the investigation of major physical and societal or environmental factors, including physical accessibility, societal attitudes and policies, and the availability of services, supports, and assistive technology that facilitate full participation.

The emphasis on social and policy barriers inherent in the new disability paradigm provides an incentive to examine the extent to which the ADA has contributed to independent living and community integration. The ADA applies a civil rights model in addressing societal policies and practices that create barriers to full participation in society. If, however, the ADA is to have a truly transformative impact on American society, there must be a vision of a nondiscriminatory society against which progress can be measured. At present, there are no real benchmarks by which to assess the ADA's impact. Evaluations tend to be in terms of "cases" handled, complaints resolved, lawsuits won, physical barriers removed, or volumes of information assembled, rather than the extent to which the ADA has resulted in greater participation in society by people with disabilities.

The growing realization of the importance of environmental barriers in disability focuses concern on environmental changes that have the potential to impede or facilitate independent living and community integration. Perhaps most striking are the continuous developments in telecommunications and information technology. Accessible computers and Internet infrastructure as well as universal or specialized communication devices afford access to information and interactions among people with disabilities, their families, advocates, service providers, employers, and others. Careful planning, based on research, will be a requirement for ensuring that new technologies increase participation rather than result in isolation for people with disabilities.

Directions of Future Research on Independent Living and Community Integration

The purposes of NIDRR's research in the area of independent living and community integration are to facilitate the participation of people with disabilities in society by:

- identifying and evaluating factors or domains of community integration and independent living, especially those aspects that lead to full participation in society;
- identifying and evaluating community support models that promote community integration and independent living outcomes for individuals with all types of disabilities and from a full range of cultural backgrounds;
- providing empirical evidence of the impact of consumer control on outcomes associated with community integration and independent living;
- assessing the impact of environmental factors on the individual achievement of community integration and independent living;
- developing and disseminating training on independent living and community integration concepts and methods for consumers, families, service providers, and advocates; and
- developing and evaluating management tools to enable centers for independent living and other community programs to support independent living and community integration.

Future Research Priorities in Independent Living and Community Integration

Research will analyze the implications of shifting from services to supports for the individual and develop an in-depth understanding of the role of supports in facilitating community integration and independent living.

Research on Community Integration/Independent Living Concepts. Both personal experience and certain academic disciplines provide guidance for understanding community integration and independent living. Development of an integrated conceptual framework will facilitate rigorous research on how to use community integration and independent living concepts to improve the lives of people with disabilities.

Additionally, research must find ways to measure these outcomes in order to evaluate services provided to people with disabilities.

Specific research priorities include:

- reviewing relevant scholarship and creating a theoretical framework for the study of community integration and independent living that incorporate the real world experiences of people with disabilities, and include knowledge gained from disability studies;

- developing measures that build upon the conceptual framework and can be applied to the evaluation of rehabilitation interventions intended to increase independence and integration; and

- analyzing cultural perspectives as facilitators or obstacles to independent living and community integration.

Research on Implementation of Community Integration/Independent Living Concepts. The independent living and community integration movements have contributed conceptual standards for evaluating disability and medical rehabilitation services and programs. Further research is needed on how to apply these standards in different real-world settings. Currently, many programs and services do not reflect these concepts and, consequently, often provide services that do not incorporate consumer direction or allow consumer choice.

Specific research priorities include:

- identification and assessment of models of service delivery that incorporate concepts of independent living and community integration and reflect an understanding of the importance of environmental barriers; and

- development and dissemination of training materials on independent living and community integration concepts for consumers, families, service providers, and advocates.

Research on Measures of Independence and Community Integration. To evaluate how programs and services contribute to the outcomes of independence and community integration, researchers, policy-makers, and consumers must have adequate measures of these outcomes. As discussed elsewhere in this plan, NIDRR is placing special emphasis on development of measures of the interrelationship between the individual and the environment. Concepts of independent living and community integration are integral to that process.

Specific research priorities include:

- development of measures of independence and community integration that are consumer-sensitive and that measure the impact of the environment and

accommodation on these outcomes; and

- evaluation of strategies to promote independence, inclusion, and participation.

Research on Physical Inclusion. Housing, transportation, communication, and architectural barriers limit the physical inclusion of people with disabilities. Lack of funding also affects access to these necessary community supports, and funding constantly changes due to policy decisions at the federal and state levels.

Specific research priorities on physical inclusion include:

- identification and evaluation of models that facilitate physical inclusion, including the development and evaluation of supported housing and transportation models that are consistent with consumer choice; and

- investigation of the impact of managed care on access to services and equipment that provide support for physical inclusion.

Research on the Impact of the ADA. The impact that the ADA has had or will have on participation in society currently is unknown. It is important to identify the obstacles to optimal achievement of the goals of the ADA.

Specific research priorities include:

- an evaluation of the impact of the ADA on community participation of people with disabilities and on the achievement of independent living and community integration outcomes;

- an examination of questions of accessible infrastructure, employment patterns, civic participation, recreational activities, societal attitudes, and policies to determine what post-ADA policy initiatives may be required to attain full participation by people with disabilities; and

- an analysis of the extent to which the ADA has affected other public policy initiatives.

Research on the Impact of Technological Innovation. While the potential benefits of technological innovations are often assumed, there also are potential issues about accessibility, equity, and application of communications technology and how these issues affect independent living and community integration.

Specific research priorities include:

- an assessment of the impact of applications of telecommunications innovations on independent living and community integration outcomes;

- an identification of barriers to participation in the community, including those resulting from inequitable distribution of technology or reduction of interpersonal contact; and

- an exploration of potential innovative applications of telecommunications and information technologies to expand opportunities for informed choice, independence, communication, and participation.

Research on Increasing Personal Development and Adaptation. NIDRR previously has funded personal skills development training to assist people with disabilities in living in the community. This training covers skills related to behavior management, communication, and productive work. In the area of behavior management for people with mental retardation and mental illness, strategies have focused on minimizing *challenging behaviors*.

Specific research priorities include:

- identification of strategies that promote the development of self-advocacy skills, including social and communication tools, to assist people with disabilities in living in community settings;

- analysis of the influences of environmental factors in developing positive behavioral support models;

- development of cost-effective techniques to foster the capacity of providers, educators, and families to prevent or respond to challenging behavior;

- assessment of the potential role of technology in promoting personal development and adaptation in community settings; and

- development of strategies and tools to improve consumer choice and decision-making about assistive technology and to assess its performance.

Research on Personal Assistance Services. It is important to test hypotheses about the role of personal assistance services (PAS) in promoting community integration, return to work, health maintenance, and the impact of PAS on the use of health care and institutionalization dollars. The relative value of different PAS systems for disabled individuals of varying ages, disability types, ethnic groups, and personal independence goals is unknown. Although research has demonstrated the impact of consumer-directed PAS models on consumer satisfaction, the relationship of satisfaction to quality of life and other outcomes measures needs further explication.

Specific research priorities include:

- evaluation of the quality of life and cost-effectiveness outcomes of consumer-directed services;
- analysis of the impact of PAS on participation in employment; and
- evaluation of the impact of assistive technology on the need for and use of PAS.

Research on Social Roles. Public policy research is needed to examine how rules and regulations of public programs affect achievement of desired roles by people with disabilities. Marriage, parenthood, and employment are among the social roles that are often discouraged by legislation, regulations, policies, and practices.

Specific research priorities include:

- investigation and documentation of the ways in which federal, state, and local legislation, regulations, policies, and practices impact on social role performance of people with disabilities; and
- identification and evaluation of tools to assist people with disabilities in fulfilling their social roles.

Research on Social Integration and Self-Determination. The abilities to form mutually rewarding and non-exploitative friendships, to recognize and express personal preferences, to evaluate options and make decisions, to advocate for oneself, and to adapt to changes in circumstances are attributes that contribute significantly to independent living and community integration.

Specific research priorities include:

- identification and evaluation of service delivery models that incorporate individual choice and consumer control into strategies for achieving social integration and self-determination;
- development of measures to evaluate independent living and community integration in terms of inclusion, social integration, and self-determination; and
- assessment of the prevalence of abuse and violence in community settings, and development of strategies to minimize their occurrences.

Research on Management Tools for Centers for Independent Living and Community-Based Residential Programs. NIDRR previously has funded research on effective management strategies for centers for independent living, as well as research on community residential living for individuals with mental retardation and long-term mental illness. Continued research in these areas will evaluate the effectiveness

of current systems and address the challenges to these programs in their expanding roles.

Specific research priorities include:

- development of strategies for centers for independent living to succeed in their roles with state rehabilitation agencies and other agencies and groups concerned with independent living;

- development and evaluation of strategies for centers for independent living and community-based residential programs to design and adapt programs that address the changing nature of the disability population;

- development and evaluation of strategies for centers for independent living to respond to increased emphasis on ADA issues, such as accommodation, accessibility, and universal design; and

- investigation of applications of new information technologies in the management of centers for independent living and community-based residential programs.

Research to facilitate community integration and independent living will focus on strategies to make communities, social systems, public policies, and the built environment more accessible to people with disabilities and more supportive of their independence and participation.

In the new paradigm scenario, the emphasis will be on supports rather than services, the managers of support systems increasingly will be people with disabilities themselves, and services originally designed for application in institutions will be adapted for use in the general community.

Chapter 7

ASSOCIATED DISABILITY RESEARCH AREAS

I make no claim, as other people with a disability might, that the essence of what I experience is inherently uncommunicable to the able-bodied world. I do not believe that there is anything in the nature of having a disease or disability that makes it unsharable or even untellable.

—Irving Zola
Late Professor of Sociology,
Brandeis University

Several important issue areas cut across the four research areas—employment, health and function, technology for access and function, and independent living and community integration—described earlier in this *Plan*. Disability statistics, disability outcomes measures, disability studies, rehabilitation science, and disability policy research all are integral to successful completion of a comprehensive agenda in disability and rehabilitation research. NIDRR will fund research efforts in each of these areas during the next five years to enhance NIDRR's overall research program and contribute to NIDRR achieving its goal of helping people with disabilities attain maximal independence. Priorities for each research area are discussed in this chapter.

Disability Statistics

NIDRR has several purposes in advancing work in disability statistics. First, NIDRR wants to make the most of the data currently collected in reliable national data sets. Second, NIDRR encourages the creation and analysis of research databases, including meta-analyses focused on problems such as employment rates or the utilization of health care or social services. Third, NIDRR seeks to understand the composition of a possible emerging universe of disability created by new disabilities or socioeconomic variations in the distribution of existing disabilities. These changing areas have implications for both public health and rehabilitation. Fourth, NIDRR wants to assist in providing input to the formulation of national disability statistics policy, including the incorporation of measures relevant to the new paradigm of disability. Finally, NIDRR recognizes the need for surveys to be conducted in accessible formats, and for disability demographic and statistical data to be readily available to a wide range of audiences.

Data about the incidence, prevalence, and distribution of disability, and the characteristics and experiences of

disabled people, are critical to planning research and services, evaluating programs, and formulating public policy. These data may be generated by diverse sources such as national population surveys, program data collection on participants, and researcher-compiled data sets relevant to specific research areas. Other less prominent sources include state and local surveys, advocacy organization data, and market research data.

Existing data resources are of varying degrees of completeness and quality, and are not sufficiently comprehensive in scope or perspective. None takes into account the new paradigm of disability that examines the interaction between the individual and the environment, and requires measures of environmental as well as individual factors that contribute to disability. NIDRR has taken a lead role in elucidating the connection between impairment and the supports or limitations imposed by the built and social environments. NIDRR will initiate the process of developing new survey measures to define disability accurately and reliably in the context of both individual and environmental factors.

Research Priorities for Disability Statistics

NIDRR will continue to support the secondary analysis of major national data sets, especially the disability supplement to the National Health Interview Survey, identifying information and connections not considered by the survey sponsors. NIDRR's other focus will be the refinement of the disability data effort to reflect new paradigm concepts. Specific research priorities include:

- the elucidation of salient issues or the stimulation of further research questions through meta-analyses;
- development and evaluation of state-of-the-art measurement tools that will assess the complex interactions between impairment and environment;
- development and evaluation of strategies to ensure that disability statistics accurately capture information on underrepresented minorities and emergent disabilities;
- development and evaluation of methods for ensuring the dissemination of disability statistical data to diverse audiences; and
- development and testing of accessible survey instruments and protocols.

Rehabilitation Outcomes Measures

The importance of demonstrating outcomes across service settings, programs, and research efforts cannot be overemphasized, given

resource allocation issues and concerns about value that operate at every level of our society. Demonstrating outcomes is an integral part of NIDRR's research agenda now and in the future. For purposes of discussion, several categories of outcomes measures are presented. In practice, however, these measures may not be mutually exclusive.

One area in which significant prior work on outcomes measures has occurred is medical rehabilitation. A number of measures have been developed and integrated into service delivery and research settings. Examples of these measures include impairment-specific measures such as the NIH Stroke Scale, disability measures like the Functional Independence Measure (FIM), and measures of handicap such as the Craig Hospital Assessment and Reporting Technique (CHART). Many of these measures, however, have been validated narrowly and are not applicable across disability groups. Some were developed for hospital settings and require revision for use in post-acute programs or in community settings.

The new focus on long-term outcomes requires measures that can document changes over time. Use of an outcomes-based approach also has ramifications for sample design, in terms of identifying homogeneous groups of consumers for comparison and using effective risk-adjustment methodologies. New managed care approaches have resulted in demands by people with disabilities for outcomes monitoring to ensure that quality care standards are met. This concern for measurable outcomes based on quality standards also is evident in the payer community, which has questioned evidence of the efficacy of treatments.

Consumers have expressed particular concern about quality assurance in the area of assistive technology. NIDRR will support investigations to identify and develop evaluation methodologies and outcomes measurement models for consumer assessments of assistive devices.

Expanding the focus of outcomes research to incorporate measures of environment and accommodation is critical to continued implementation of a new paradigm of disability. Currently, our ability to describe the interaction of an individual and the environment is limited by a lack of validated measures. A number of conceptual and methodological concerns must be addressed in developing such measures. Of particular relevance is how best to account for the impact of numerous variables, including environmental factors, that impinge on long-term outcomes.

Independence and community integration have been identified as overarching NIDRR goals, and NIDRR's research initiatives relate

directly to supporting the achievement of these goals. As indicated earlier, some measures of community integration are already in use. These measures, developed for specific populations, are examples of tools that might be refined to monitor and compare progress toward the goals of independence and community integration.

Distinctly related to functionally oriented medical outcomes measures are measures of quality of life. These measures are conceptually linked to individual values about living with disability and include the impact of rehabilitation and environmental barriers. A particular challenge in developing these measures is the qualitative nature of individual valuation of life quality and the difficulty of constructing ways of comparing individual perceptions.

Research Priorities for Rehabilitation Outcomes Measures

NIDRR will support research and development activities that increase the availability of measures across the areas discussed in this section. Specific research priorities include:

- refinement of measures of medical rehabilitation effectiveness to incorporate environmental factors in the assessment of function;
- development and evaluation of measures of independence, community integration, and quality of life, especially measures that incorporate the perspectives of people with disabilities; and
- development of measures for use in outpatient and community-based settings, ensuring the applicability of these measures to all disability populations.

Disability Studies

The field of disability and rehabilitation research has not reached a general consensus on the meaning of the term *disability studies*. NIDRR uses the term generally to refer to the holistic study of the phenomenon of disability through a multidisciplinary approach. This approach emphasizes the perspectives of people with disabilities and regards personal experience as valuable data.

The IOM, in *Enabling America*, describes disability studies as "the examination of people with disabling conditions and cultural response to them through a variety of lenses, including economics, political science, religion, law, history, architecture, urban planning, literature..." (Brandt & Pope 1997). NIDRR believes that disability studies is a natural complement to the new paradigm, emphasizing the study of the complex relationship between various aspects of disability and

society, and that it will enhance the methodologies and knowledge base of each involved scientific discipline.

In this respect, the content of disability studies is not unlike that of other area studies, such as women's studies, African-American studies, or geographic, regional, or ethnic studies (e.g., Middle Eastern studies or Islamic studies). All of these areas of study require the convergence of theory, technique, and methodology from a range of disciplines to develop an enhanced understanding of a complex phenomenon.

An important purpose in the development of any area of study is to assure that the perspective of the group under study is reflected in the methodology and body of core knowledge, and that individuals from the group have the opportunity to participate in the development and promulgation of the methodologies and the curricula. This also can be expected to lead to an impact on core disciplines, specifically an impact that requires development of theories and hypotheses that do not ignore the subject population. For example, women's studies has influenced the development and legitimation of studies of the sociology of gender. Economists analyzing poverty now must consider the particular causes and effects of poverty among women and in ethnic groups, largely due to the attention and legitimation of these subjects by the area studies efforts.

NIDRR has three basic purposes for supporting a program of disability studies. First, disability and rehabilitation research needs a body of knowledge that is comprehensive and holistic, reflecting a range of disability perspectives, and it needs a larger cadre of researchers and policy-makers familiar with that knowledge base. Second, the field of disability and rehabilitation research needs to develop methodologies and influence the theories and practices of a range of disciplines to ensure their constructive attention to the issues related to disability, thereby enhancing the scientific endeavor. Third, consistent with the goals of the Rehabilitation Act, as amended, especially its principles of inclusion, integration, and independence, NIDRR believes it is essential to reflect the perspectives of individuals with disabilities in studies of disability. NIDRR also believes it is important to afford increased opportunity for individuals with disabilities to participate in the development of curricula and methodologies to study the phenomenon of disability.

Research Priorities for Disability Studies

Specific research priorities for disability studies include:

- the development of a theoretical framework for conducting disability studies and strategies for teaching disability studies at

various academic and non-academic levels;

- the compilation of information about the many forms of extant disability studies, including academic levels, disciplines involved, course content, resources, and students; and

- the exploration of the feasibility of developing non-academic courses in disability studies that will facilitate the study of the experience, history, and culture of disability in community-based settings.

Rehabilitation Science

Permeating NIDRR's research agenda will be an awareness of opportunities to construct and test a theoretical framework for rehabilitation science. As defined in the 1997 IOM report, *Enabling America*, rehabilitation science is a study of function, focusing on how disability develops, and the factors influencing these processes. The goals of rehabilitation science are to contribute to better treatment and technology for people with disabilities. Rehabilitation science focuses on factors that lead to transitions along a continuum from underlying pathology to functional and environmental limitations to functional independence and participation. These factors include impairment, functional limitation, and disability. In addition, rehabilitation science analyzes physical, behavioral, environmental, and societal factors that affect movement along the continuum (Brandt & Pope 1997). The field of rehabilitation has produced a body of empirical evidence regarding function and interventions to improve function. The next challenge is to use this evidence to produce a body of scientific and engineering theory that can be used to develop innovative and improved techniques of functional restoration.

Research Priorities For Rehabilitation Science

Specific research priorities for rehabilitation science include:

- further elucidation of the enabling-disabling process; and

- exploration of the development and application of a theoretical framework for rehabilitation science.

Disability Policy

Public disability policy broadly defines the participation of disabled people in the general benefits that society provides to all citizens, as well as the parameters of disability-specific benefits. Public policy has more significance for people with disabilities and their families than for many segments of the population. This differential impact stems, in part, from the fact that people with disabilities must interface with so many different

components of public policy systems, many of which are conflicting or inconsistent, such as employment goals and requirements for income assistance programs. The larger public policy context for disability and rehabilitation research reflects interlinking service delivery systems in which changes in one system often have a substantial impact on others. The dilemma for disability and rehabilitation policy is that the various systems are not mutually reinforcing.

The lack of mutual reinforcement stems from four factors. First, policy goals may be, to some degree, mutually exclusive; that is, policies designed to emphasize one goal may be implemented only at the expense of other goals. Second, different policies are governed by different and conflicting assumptions about disability and the role of people with disabilities in American society. Third, some service systems lack integration with other systems and programs needed to promote continuity between different parts of people's lives. Fourth, disability largely has been ignored in national science and technology policy. Thus, underlying conflicts may exist and result in unintended disincentives to work and to attain independence.

At the systems and societal levels, the potential impact of policy initiatives on people with disabilities may be even more significant, yet it is less likely to be recognized. The impact of telecommunications, the built environment, health care, and labor market policies has been discussed in this plan.

Research Priorities For Disability Policy

Disability policy research should examine issues that are national in scope and that represent intersections of public interest. Such research should use national data sets, where possible, to determine the impacts of policy decisions on people with disabilities.

Specific research priorities include but are not limited to:

- analysis of how the bundling of income supports with other benefits—including health insurance and other in-kind assistance such as housing subsidies or food stamps—affects individual decisions to seek or continue employment;

- evaluation of the impact of changing social policies toward parenting, personal assistance services, tax deductions, and education, among other factors, on the lives of people with disabilities;

- analysis of the impact of welfare-to-work initiatives on the well-being of people with disabilities or their families;

- evaluation of the impact of macroeconomic issues, such as

the changing labor force requirements, on employment opportunities for people with disabilities;

- evaluation of the impact of legislation and policy on employers, professional service providers, social service agencies, and direct support workers in terms of their participation in employing, serving, or working for disabled people;

- investigation and evaluation of the relevance of frameworks for disability research, including but not limited to research on the role of market forces (balancing supply and demand) on disability policy;

- investigation of the impact of national telecommunications and information technology policy on the access of people with disabilities to related education, work, and other opportunities; and

- examination of the impact of national housing policy and building codes on the living environments and housing choices of people with disabilities and their families.

Related disability research emphasizes knowledge areas that are crosscutting and essential to the support and refinement of disability research in general. The common theme linking disability statistics, outcomes measures, disability studies, rehabilitation science, and disability policy is that they all provide essential frameworks and building blocks that enable the disability research enterprise to thrive and to address important issues in meaningful ways.

Section Three: Priorities for Related Activities

The Rehabilitation Act authorizes NIDRR to conduct research and related activities. This section focuses on the related activities that complement NIDRR's research component and support its overall mission. NIDRR has organized the related activities section into three areas: knowledge dissemination and utilization, capacity-building, and enhancing NIDRR's Management of Research.

The 1992 amendments to the Rehabilitation Act charged NIDRR with ensuring the widespread dissemination, in usable and accessible formats, of practical scientific and technological information to a wide range of audiences. NIDRR's comprehensive program of knowledge dissemination and utilization projects addresses this mandate. Capacity-building activities center primarily on NIDRR's training function. The Rehabilitation Act mandated the training of researchers, service providers, and consumers and their families to strengthen research capability and improve the effective use of research results in practice. NIDRR sponsors a variety of programs and strategies to build capacity in the rehabilitation field and in the disability community. The area of enhancing NIDRR's management of research includes internal and external activities implemented by NIDRR to achieve its goals and objectives. Interagency coordination, planning, evaluation, and advanced technological communications with and among grantees are key strategies employed to leverage effectively the benefits of NIDRR programs.

Chapter 8

KNOWLEDGE DISSEMINATION AND UTILIZATION

Our mission at the Office of Special Education and Rehabilitative Services is to ensure that people with disabilities become fully integrated and participating members of society. Dissemination and utilization are the tools through which we do this.

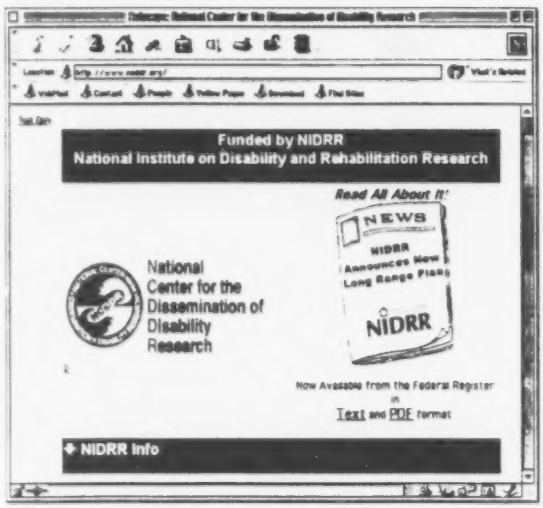
—Judith E. Heumann
Assistant Secretary, OSERS

Overview

The effective dissemination and use of disability and rehabilitation research are critical to achieving NIDRR's mission. Research findings can improve the quality of life of people with disabilities and further their full inclusion into society only if the findings are available to, known by, and accessible to all potential users.

NIDRR supports a strong dissemination and utilization program that reaches its many constituencies: research scientists, people with disabilities, their families, service providers, policy-makers, educators, human resource developers, advocates, entities covered by the ADA, and others. In carrying out this mission, NIDRR's challenge is to reach diverse and changing populations, to present research results in many different and accessible formats, and to use technology appropriately.

The Rehabilitation Act's 1992 amendments included language requiring NIDRR to ensure the widespread distribution, in usable formats, of practical scientific and technological information generated by research, demonstration projects, training, and related activities. In addition, NIDRR's responsibilities were amended to emphasize wide dissemination of educational materials and research results to individuals with disabilities,



The National Center for the Dissemination of Disability Research, like other NIDRR grantees, maintains a Web site to communicate information quickly.

especially those who are members of minority groups or of unserved or underserved groups. In addition, the statute requires Rehabilitation Research and Training Centers (RRTCs) to serve as information and technical assistance resources to providers, individuals with disabilities, and others through workshops, conferences, and public education programs. Rehabilitation Engineering Research Centers (RERCs) disseminate innovative ways of applying advanced technology. RERCs also must cooperate with projects funded under the Assitive Technology Act of 1998 to provide information on, and increase awareness of, assistive technology.

Effective dissemination employs multiple channels and techniques of communication to reach intended users. This chapter addresses strategies and techniques to disseminate information to a wide range of target audiences and to promote the utilization of this information. These strategies take into account a range of uses—conceptual or practical, total or partial, converted or reinvented. The strategies also incorporate innovative technologies to enhance direct access by diverse groups. Additionally, this chapter outlines NIDRR's proposed research agenda for dissemination and utilization activities.

The Knowledge Cycle—The Role of Dissemination and Utilization

The components of the knowledge cycle are knowledge creation, knowledge dissemination, and knowledge utilization. The concept of the cycle implies continuous interaction among its parts. At NIDRR, knowledge creation results from funded research and training programs, and staff activities. The challenge of NIDRR's dissemination and utilization activities involves transferring this knowledge, targeted to specific user populations, to improve the lives of people with disabilities.

Effective dissemination requires understanding that communication channels are expanding continuously and range from personal communications to mass media (e.g., print, radio, television, the emerging information superhighway, and the merging of these and other communications technologies). To choose the most effective communication strategy, it is helpful to identify clearly the intended audience (e.g., scientists, service providers, people with disabilities); the context for use (e.g., home, work, community); and the characteristics of the information to be disseminated (e.g., type, use, relative advantage, compatibility, complexity).

Knowledge utilization activities focus on ways to facilitate use of

research results, new technologies, and effective practices or programs. To be used, knowledge must relate to a perceived need, must be understandable, and must be timely. Thus, awareness of potential uses for the information should influence research design and materials development, keeping in mind that flexibility is important because there may be unanticipated audiences for the material. Selecting dissemination strategies that relay information quickly is equally important.

The Changing Environment For Dissemination

The environment in which dissemination and utilization strategies operate is undergoing a number of changes, including technological innovation, the changing etiology of disability, and an increased emphasis on the individual's interaction with the physical and social universe. These changes must be factored into future dissemination and utilization approaches.

As Paisley notes, "Many of the problems that challenge knowledge utilization have changed little since the 1960s and 1970s; however, the communications environment of knowledge utilization has changed dramatically (Southwest Educational Development Laboratory 1996)." Consumer demand for direct and rapid access to information, and the technological capacity to disseminate information simultaneously and inexpensively to mass audiences through electronic media, such as the World Wide Web, are changing dissemination and utilization strategies. The Internet, a beginning step in the creation of the global information superhighway, is open to anyone with a computer, modem, and telephone. The number, sophistication, and accessibility of Internet sites serving the information needs of people with disabilities are increasing rapidly.

These innovations permit NIDRR projects and centers to communicate more easily with larger numbers of targeted users at all phases of the research process; however, this proliferation raises difficult questions about equity, access, and effectiveness (Southwest Educational Development Laboratory 1996).

Changes in the prevalence and distribution of disabilities are influencing NIDRR's research. An emerging universe of disabilities, incorporating disabilities related to underlying social and environmental conditions, such as poverty, isolation, and aging, has created new targets for the dissemination of research findings.

Finally, there is increased recognition of the importance of an ecological science model that focuses on relationships and interactions that influence, and are influenced by,

the environment of an individual, organization, or community. Research affects society; society, in turn, affects what is studied and how it is studied. NIDRR supports research that is issue-based and flexible to facilitate timely responses to environmental changes and timely contributions to society.

Dissemination and Utilization Strategies for the Future

In response to the needs of constituencies and to the changing physical and social environment, future dissemination and utilization strategies will build upon successful past strategies, while capitalizing on the potential of electronic media and other telecommunications innovations. These strategies must provide accessible formats for new population groups and for individuals with cognitive or sensory disabilities.

To be successful, NIDRR grantees need assistance with the early integration of dissemination and utilization features into research projects. NIDRR will continue efforts to increase the capacity of consumers to access and use research-based information. Finally, NIDRR will support research that will determine effective dissemination methods and evaluation techniques.

In the section that follows, a number of dissemination and utilization activities are proposed. These proposed activities reflect NIDRR's concerns about the importance of dissemination in making research usable to its constituencies.

Dissemination of Research Findings

To enhance the dissemination and utilization of research, NIDRR will undertake a number of activities, including establishing a national information center, creating databases, developing consumer partnerships, providing specialized assistance to grantees, using electronic media and telecommunications, targeting new audiences, and evaluating dissemination methods.

Establishing a National Dissemination Center. NIDRR will establish a national dissemination center to address long-term dissemination and utilization objectives for individuals, groups, and communities that represent diverse geographic, multicultural, and socioeconomic populations. This center will provide technical assistance to grantees to improve their dissemination activities; conduct selected national dissemination projects; and serve as a resource on dissemination theory, new dissemination techniques, and evaluations of dissemination strategies. The center will maintain a Web site and will work with groups of NIDRR grantees—for example, the Model Projects for Spinal Cord Injury—to develop accessible, special-focus Web sites.

In addition, the national dissemination center will:

- disseminate research findings that have been published in refereed academic journals by NIDRR researchers;
- translate complex research findings into an accessible language and format in consumer-oriented publications;
- maintain a library and information center, such as the National Rehabilitation Information Center (NARIC), with archival and bibliographic retrieval capacity; and
- determine markets for NIDRR-funded research products and appropriate strategies for reaching these markets.

Using Databases and Key Publications. To support knowledge dissemination and extend the availability of research products, NIDRR will:

- maintain a database of assistive technology products, such as ABLEDATA, that is accessible to consumers and service providers, and available on the Internet;
- make key publications, such as NIDRR's *Program Directory* and *Compendium of Research Product from NIDRR Grantees and Contractors*, available on the Internet; and
- establish a management database to track dissemination activities and to identify research results suitable for further dissemination.

Developing Consumer Partnerships. To enlist the target populations in ensuring that disseminated research findings are relevant, accessible, and useful, NIDRR will:

- explore the potential for developing partnerships with centers for independent living and state vocational rehabilitation agencies to identify, repackage, and market information specific to their needs;
- provide technical assistance to community organizations or public agencies to facilitate the adaptation of research findings into practical use; and
- provide technical assistance and training to consumers and consumer organizations on accessing, interpreting, and using new information. Training includes the use of electronic information sites and how to provide feedback to the research process.

Providing Specialized Assistance to Grantees in Their Dissemination Roles. NIDRR centers and other grantees are important information resources.

To enhance their productivity in disseminating their research results, NIDRR will:

- promote the publication of research findings in scientific journals and in consumer-oriented publications;
- provide technical assistance on accessibility and marketing;
- develop intercenter and interproject linkages for routine communication and information-sharing;
- assure the timely availability of research findings and products in usable form for targeted user groups; and
- provide technical assistance on dissemination and utilization processes to constituency groups.

Using Electronic Media and Telecommunications. Exciting developments in information technology greatly enhance the possibility of reaching more research information users in efficient and effective ways. To capitalize on this potential, NIDRR will:

- explore the feasibility of an Online Disability News Service, focusing on government-funded research data; funding opportunities; updates from the legislative, judicial, and executive branches of government; awards; achievements; current issues; and problem-solving attempts;
- initiate activities to improve the portrayal of individuals with disabilities in the media, including specialized media efforts directed toward the nation's youth or diverse cultural groups;
- examine the role of distance learning approaches in dissemination;
- explore communications strategies for effective Internet searches for disability-related information, including directories of sites and a thesaurus of key words; and
- provide technical assistance and training to consumers and consumer organizations on accessing, interpreting, and using new information, including training on the use of electronic information sites. Emphasize ways to increase access among elderly and minority consumers to the Internet and other electronic media.

Reaching Out to New Audiences. The changing nature of disability and of the disabled population requires thoughtful efforts to reach new audiences. To facilitate these efforts, NIDRR will:

- ensure the accessibility—both in format and content—of all

products disseminated by NIDRR and its grantees. This may include the use of alternate formats (e.g., Braille, large print, audiotape, captioned videos) or the use of language that is appropriate for people with cognitive impairments or who are non-English-speaking;

- improve the dissemination of information from NIDRR-funded projects to consumers with culturally diverse backgrounds as well as to elderly people, newly disabled individuals, and other people with disabilities who may not be reached by traditional dissemination methods;

- address general audiences that influence the opportunities available to people with disabilities. These general audiences include employers, manufacturers, educators at all levels, economic development and planning personnel, service establishments, the media, and policy-makers at local, state, and national levels; and

- explore ways to involve people with disabilities in all aspects of the research cycle.

Evaluation of Dissemination Methods. Finally, while commercial media efforts are regularly evaluated, little has been done to assess the effectiveness of research dissemination strategies in the disability field.

Given the central importance of dissemination to its broad constituency, NIDRR will:

- conduct projects to advance theory development in dissemination and utilization and to evaluate the application of the various dissemination and utilization approaches;

- test methods for measuring the utilization and impact of research results for different target audiences; and

- evaluate the appropriateness and effectiveness of Web-based dissemination and distance education models for conveying information to the range of target audiences.

Chapter 9

CAPACITY-BUILDING FOR REHABILITATION RESEARCH

Overview

To ensure that research improves the lives of individuals with disabilities, NIDRR will support efforts to enhance the capacity of the field to conduct research that is scientifically excellent and relevant to the concerns of disabled individuals, service providers, and the science community. Capacity-building involves training those who participate in all aspects of the disability research field, including scientists, service providers, and consumers.

For the future, training efforts will be based on the new paradigm of disability and emphasize cross-disciplinary collaboration and participatory research. They will take into account trends in science, society, and disability culture itself. NIDRR will make creative use of funding mechanisms to meet these challenges.

Priorities in Capacity-Building

NIDRR's capacity-building responsibilities are multifaceted. Its principal statutory mandate for training is to support advanced instruction for researchers and service providers. NIDRR also has an implied mandate, strengthened in the 1992 amendments, to train consumers in the applications of new research knowledge and in the uses of assistive technology.

To advance the disability and rehabilitation field, NIDRR will expand the scope of its capacity-building activities to:

- raise the level of rigorous qualitative and quantitative research and increase the use of state-of-the-art methodologies by providing advanced training in disability-related research for scientists, including those with disabilities and those from minority backgrounds;
- teach researchers to conduct research that explicates disability as a contextual phenomenon;
- prepare researchers to conduct disability studies that are holistic, interdisciplinary, and cognizant of the cultural context of disability;
- develop the capacity of researchers to conduct studies in

new settings, (e.g., homes, workplaces, schools, recreational facilities, community-based organizations);

- train rehabilitation practitioners in the application of research-generated knowledge and new techniques; and

- train consumers, family members, and advocates how to use research findings, in part to facilitate participatory research efforts.

Additional information on each of these priority areas is provided in the following sections.

Training for Advanced Research Studies

It is crucial to NIDRR's mission that research in disability and rehabilitation reflects sound scientific practices and uses rigorous qualitative and quantitative methods. Adherence to sound methodology and research design strengthens the credibility of NIDRR's research and, consequently, the ability of NIDRR's constituencies to use the research findings in advocacy, service delivery, and policy-making. To this end, NIDRR will increase its emphasis on scientific rigor in generating research agendas and in reviewing research applications. Scientific rigor may encompass methodological approaches such as controlled studies, longitudinal studies, or increased sample sizes. Constructing carefully defined hypotheses tied to theory is an important element in improving research methods. For qualitative research efforts, rigor includes strict adherence to analytical frameworks, improved data collection methods, and careful selection of subjects.

The capability to conduct first-rate research depends on a commitment to learning the multiple skills required for designing scientific studies, selecting appropriate research methods, analyzing data, and interpreting findings. NIDRR will continue its support of research training initiatives, including those that emphasize research training opportunities for minorities and people with disabilities. This training focus reflects NIDRR's commitment to participatory research methods that enhance the relevance of research findings.

Training in the Application of Research Findings

The NIDRR Rehabilitation Research and Training Centers (RRTCs) will advance further the statutory requirement to train service providers in the application of research findings to real-world needs of people with disabilities. Training can occur at many levels, including pre-service, graduate, and in-service. NIDRR will support training aimed at transferring research findings into practical use. Such training must be sensitive to the rapidly changing

service delivery environment, which is de-emphasizing inpatient care and experiencing growth in post-acute and community settings.

Training in New Paradigm Research

As discussed throughout this plan, the new paradigm conceives of disability as a function of the interaction between impairments and other personal characteristics, and the larger physical, social, and policy environments. Unidimensional and static measures of function, improvement, outcomes, and other aspects of disability and the rehabilitation process will not be sufficient.

Any paradigm of science that limits research to modifying the disabled person's functions without equally emphasizing the need to change the person's environment cannot capture the important phenomena associated with living as a disabled individual. Nor will it accommodate scientific and social advances in the multiple, interactive sectors of society that will characterize life in the future. Although developments in both the biological and biomechanical sciences will bring new treatments and devices that will improve personal functions, these advances must be adjusted to meet the demands of the person living in his or her environment of choice, doing activities that are of significance to that individual.

A framework for asking new questions for NIDRR-funded research has been provided by the major provisions of the ADA. Researchers must develop measures that capture the contributions of the social and physical environments to the disability. The need for researchers capable of investigating disability in context, and explaining the adapting process, has several implications for the research training endeavor. The training must:

- emphasize interdisciplinary research and design of methodologies that can test complex hypotheses;
- attract researchers from disciplines that are not usually involved with disability and rehabilitation research. These include law, economics, architecture, business, marketing, demographics, public policy, and administrative sciences, among others;
- incorporate an understanding of disability policy and disability studies among researchers in all disciplines;
- apply the principles of the ADA—universal access and accommodations—in all research areas;
- include consumers in the research endeavor; and

- focus on the adapting process, which refers to adjusting to changes. The interaction of these changes provides the basis for understanding how best to proceed in improving participation in society among people with disabilities.

Supporting Disability Studies

The cultural context of disability is a key element in the emerging field of disability studies. Major societal changes have influenced how disability is perceived by those with disabilities and by those who study people with disabilities. People with disabilities are now viewed as individuals who are adapting to challenges (e.g., personal assistance services, use of assistive technology, access, accommodations, civil rights) in their response to society (e.g., sociopolitical analysis of activism, disability culture, independent living), and in society's response to them (e.g., stigma, policy, economics, transportation, housing). The merging of these issues into an encompassing academic area is the genesis of disability studies.

In disability studies, there is a convergence of theory, technique, and methodology from a range of disciplines to enhance one's understanding of a complex phenomenon. The perspective of the subject group in disability studies is reflected in the methodology and body of core knowledge. Individuals from the subject group must have the opportunity to participate in the development and promulgation of the methodologies and the curricula.

NIDRR has four long-term objectives for providing priority support to this area:

- creation of a body of knowledge that is comprehensive and holistic;

- training of a cadre of researchers and policy-makers familiar with that knowledge base;

- inclusion of the perspectives of individuals with disabilities in designing curriculum and research to reflect the experiences of people with disabilities; and

- creation of opportunities for individuals with disabilities to study, in a variety of settings, the history, politics, economics, sociology, literature, culture, psychology, and other aspects of disability.

Increasing Capacity for Research Under New Conditions

The research questions and the types of training needed for rehabilitation professionals will change as the paradigms of science change and economic realities force reductions in the duration of

rehabilitation service programs. Many rehabilitation researchers today are accustomed to conducting research in hospital-based or other clinical sites, applying methodologies and protocols developed in these traditional settings.

In the future, sites for conducting research and for training new rehabilitation scientists will be homes, workplaces, schools, recreational facilities, and community-based support programs. This change involves adapting to reduced access to subject and control groups, working with paraprofessionals and disabled peers in the data collection effort, and working with shared or preexisting databases.

Increasing Consumer Capacity and Participatory Research

Consumers and consumer organizations have important roles in the research endeavor, including planning research priorities, assessing real-world relevance, and educating researchers in the realities of their aspirations, needs, obstacles, and daily living conditions. Consumers also must review and evaluate research findings and reinterpret them for application to their lives. Finally, consumers can disseminate and advocate for research. The disabled individual as a whole person operating in a given environment is the focus of NIDRR's research, and it is important that individuals with disabilities willingly provide data about themselves in the role of research subjects.

Consumers are more likely to trust the research endeavor if they believe it is relevant to their needs or if researchers are appropriately sensitive to their concerns. NIDRR will continue to take an active role in forging cooperative partnerships between researchers and the disability community. These endeavors must feature an honest and respectful exchange of knowledge and seek cooperative endeavors around common ground. Studying the social, contextual, and environmental aspects of disability provides a promising impetus for the new, strengthened partnership. NIDRR will support participatory research and disability studies as strategies to achieve the goals of an informed and active consumer community. Education, training, awareness, and partnerships are among the techniques that will be used to address this goal.

NIDRR has supported the principle of appropriate and effective participatory research; that is, research that incorporates the perspectives and efforts of people with disabilities. Participatory research is evaluated by standards of scientific excellence and real-world relevance. NIDRR grantees have developed a number of innovative approaches to implement this principle of participatory research. Additional studies of participatory research concepts, fundamental

principles, operating guidelines, and most appropriate applications will enhance its future use. NIDRR will sponsor research on the conditions under which participatory research enhances the process and improves the products of research. NIDRR will sponsor research, development, demonstration, and dissemination efforts to enhance the understanding of participatory research applications and techniques.

Funding Mechanisms to Enhance Capacity-Building

Clearly, a shift has occurred in the social and scientific paradigms used to define, study, and explain disability. Consequently, the training models, research methods, and issues studied also must change.

Funding excellent research projects depends, to a large extent, on the quality of grant applications. In turn, the subject matter and quality of research reflect the competencies the investigators acquired in their training. The context for training is nested in the types of programs funded by NIDRR. NIDRR will expand these existing mechanisms—RRTCs, RERCs, Advanced Rehabilitation Research Training Grants (ARRTs), Switzer Fellowships, the NIDRR Scholars Program, and the Minority Development Program—to help meet future challenges.

Rehabilitation Research and Training Centers and Rehabilitation Engineering Research Centers

NIDRR has a long tradition of funding RRTCs at universities, medical rehabilitation facilities, and vocational and social service agencies. Recently, training has been given increased importance in the mission of the RERCs as well. Enhancing the capacity to conduct disability and rehabilitation research requires planning and coordination of three key components of research training: mentors and trainers, relevant topics, and appropriate sites.

NIDRR Centers have the critical mass of expertise and knowledge to provide:

- advanced, experiential training for researchers;
- classroom training for researchers and clinicians at undergraduate and graduate levels;
- short-term training to teach scientists new methodologies;
- in-service training for rehabilitation practitioners;
- training for consumers, their families, and representatives in implications and applications of new research-based knowledge;

- community-based training in disability studies and related areas, particularly in those centers with a strong focus on independent living, community integration, and policy issues;

- education and training in disability professions and in disability research for individuals with disabilities and for minority individuals; and

- training of rehabilitation educators and educators in a range of related disciplines.

Advanced Rehabilitation Research Training Grants

ARRTs will provide advanced research training that integrates disciplines; teaches research methodology in the environmental, or new paradigm, context; and trains researchers in disability studies and rehabilitation science. These training programs must operate in interdisciplinary environments and provide training in rigorous scientific methods.

Mary Switzer Fellowships

These fellowships will augment scholarly knowledge in the field, and function in an integrative capacity to define new frontiers of disability and rehabilitation research. NIDRR plans to provide more opportunities for interaction among the fellows and for exposure to established researchers and policy-makers.

NIDRR Scholars Program

This program will recruit undergraduates with disabilities to work in NIDRR-funded centers and to develop projects that will expose them to disability and rehabilitation research issues, while at the same time providing work experience and income. This program is an innovative approach aimed at generating interest in research careers for people with disabilities.

Minority Development Program

This program has focused on Historically Black Colleges and Universities and institutions serving primarily Hispanic, Asian, and American Indian students. NIDRR will evaluate this program to determine the extent to which it is achieving the objectives of Section 21 of the Rehabilitation Act and to implement necessary strategies to enhance outcomes. Meanwhile, NIDRR is implementing new strategies for capacity-building among minority researchers focusing on collaboration, exchange of expertise, and advanced training.

New Technologies for Training

Educators, students, clinicians, scholars, and consumers are turning more frequently to the use of new media and telecommunications technology for conveying

information and imparting skills. NIDRR respects the efficiency and impact that distance learning and Web-based education can achieve. As a research institute, NIDRR also will undertake evaluations of the effectiveness of using these techniques with various types of trainee populations, subject matter, and objectives.

Chapter 10

ENHANCING NIDRR's MANAGEMENT OF RESEARCH

Overview

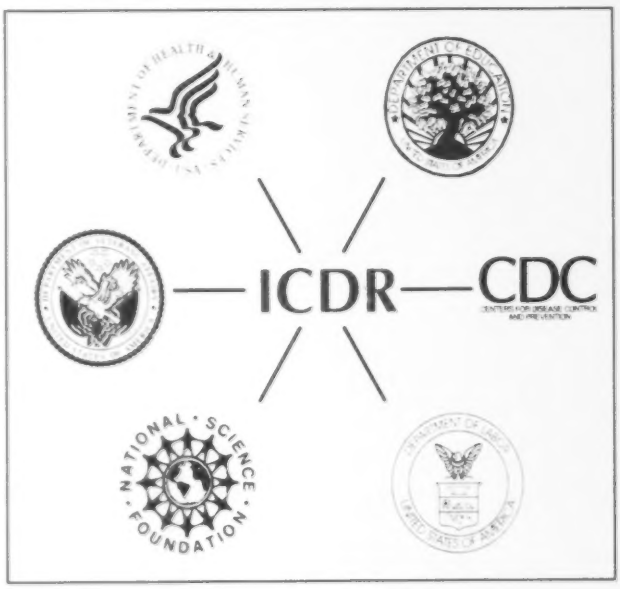
The research endeavor benefits from thoughtful management practices specifically tailored to enhance relevance, importance, scientific quality, coordination, participation, flexibility, productivity, and communication. This plan already has addressed such elements of management improvement as using appropriate modes of participatory research, expanding dissemination and utilization of research, and enhancing capacity-building, which are all part of NIDRR's programmatic efforts. This section of the plan focuses on several additional management strategies that NIDRR will use to enhance its programs.

Management Strategies

NIDRR will employ a number of management strategies in support of its five-year agenda. Among these are an emphasis on Centers of Excellence; enhanced coordination of federal disability research; improved program evaluation and performance review; enhanced peer review process; increased collaboration, including interdisciplinary and cross-disciplinary research; creative funding mechanisms; international research; innovative strategies to manage intellectual property; expanded use of information technology; the reallocation of resources; and continuous participatory planning.

Centers of Excellence

NIDRR is committed to regenerating a network of Centers of Excellence in disability and rehabilitation research. The term Center of Excellence is used widely in research and medical fields and may indicate either a judgment or an aspiration. NIDRR believes the disability constituency deserves Centers of Excellence and is applying standards and procedures



to ensure that all research, dissemination, technical assistance, and model service centers will develop and adhere to standards for Centers of Excellence. In 1988, an independent evaluation of the RRTCs developed a set of standards for an RRTC Center of Excellence. These standards included items of research administration, balance of activities, synergy, accountability, coordinated programs, and capacity to improve rehabilitation.

Recognizing that Centers of Excellence result from a partnership between NIDRR and its grantees, NIDRR has revisited the concept of Center of Excellence in its new program review process, described later in this section. The program review process has led to the further identification and development of the criteria needed to set up and operate Centers of Excellence. Essential criteria for excellence are described below.

Excellence in Administration

- Support from an appropriate host institution
- Appropriate process for research management and quality control
- Ability to leverage resources and attract funding from other sources
- Involvement of multiple disciplines
- Outcomes-oriented evaluation
- Protection of human subjects

Excellence in Scientific Research

- Expertise in and contribution to state-of-the-art research
- Application of appropriate and rigorous scientific methods, whether quantitative or qualitative
- Advancement of theory and knowledge base in the field
- Expansion of research tools and methods
- Professional recognition and publication
- Outstanding investigators

Excellence in Relevance and Productivity

- Responsiveness to priority
- Utility to consumers
- Development of knowledge to improve rehabilitation
- Systematic dissemination of knowledge in relevant and accessible formats
- Involvement of individuals with disabilities in all phases of the research process

Excellence in Capacity-Building

- Provision of advanced research training for staff, including people with disabilities and minorities
- Provision of training to service providers on using results of research efforts
- Provision of training to consumers in the uses of research
- Infusion of disability knowledge into other research areas

NIDRR will continue to refine the concept of Centers of Excellence through ongoing dialogue with its centers and other science organizations, and will adapt the concept for RERCs, model systems, and other major NIDRR programs.

Enhancing Coordination of Federal Disability Research

Congress recognized the importance of coordination among the range of agencies in the area of disability research by establishing, in Sec. 203 of the Rehabilitation Act of 1973, an Interagency Committee on Disability Research (ICDR), to be chaired by the director of NIDRR.

The statute lists the required membership in the ICDR—the 11 federal agency senior officers—and charges the committee to identify and seek to coordinate all federal plans and projects in disability research, after receiving input from disabled individuals. The ICDR, which has 35 agencies as invited participants, has adopted by consensus a set of objectives and some specific operating procedures. The ICDR objectives are:

- to avoid duplication of efforts in disability research;
- to identify gaps in research;
- to identify opportunities for research collaboration;
- to develop mechanisms for and facilitation of disability research collaboration;
- to promote synergy through combined resources;
- to share information and research findings to build a more systematic and cohesive federal effort;
- to comprise an identifiable entity that can disperse information to consumers, the private sector, policy-makers, and the public about government-wide activities; and
- to assist in developing a responsive and relevant federal infrastructure for disability research, by reporting to the Congress and the president, federal agencies, and the public.

Coordination of related activities in disparate public programs is an ongoing challenge. The scope of disability suggests that many diverse agencies will be involved in providing services and conducting research on relevant issues. This involvement is both inevitable and desirable. Disability is at least a peripheral concern for many agencies whose central missions lie elsewhere—for example, the Departments of the Interior, Justice, and Transportation; the Federal Communications Commission; and the Federal Aviation Administration. Disability is closer to the core, but

still not the primary mission of agencies such as Social Security Administration, Health Care Financing Administration, and the Administration on Aging. This dispersion of resources and authorities may benefit disabled people by ensuring that their concerns are recognized and dealt with by a wide array of mainstream agencies. Diverse constituencies also benefit from multiple avenues of access to research funding, policy-making, and services.

Potential benefits of effective coordination of these diverse agencies include opportunities to address a common problem with a critical mass of resources; avoid unintended and wasteful duplication; exchange information in a system that increases all parties' awareness of issues; support complementary and synergistic research; leverage resources or provide joint funding of research; and develop a level of informed policy-making and leadership for the field.

The ICDR can play several roles while coordinating activities in disability research. The ICDR can educate federal agencies and others about disability issues; take the lead in modeling accessibility; advance important concepts such as universal design or the new paradigm of disability; and promote achievement of the goals of the ADA. The ICDR focuses efforts on gathering information about disability research and making it available to a wide range of interested agencies.

The ICDR will focus on issues that concern the missions of many agencies in cooperating to build collaborations. Disability statistics and capacity-building in disability research are examples of two issues to be addressed by the ICDR in the next five years. All ICDR agencies and other constituents need disability statistics in their planning, policy-making, resource allocation, and progress evaluations. Most of these agencies also have responsibility for collecting statistics about disability or, at least, collecting program data about disabled participants. The ICDR will focus on improving the relevance of data collection efforts to the new paradigm of disability, the emerging universe of disability, the goals of the ADA, and NIDRR's goals of increased independence, productivity, and inclusion.

Similarly, each agency that supports disability research has a stake in ensuring the existence of a cadre of highly qualified researchers to investigate issues related to medical and vocational rehabilitation, health care, societal supports, employment, accessible environments and technology, and civil rights. The ICDR can leverage the investment of federal dollars in training through cooperative strategic planning and coordinated program implementation, such as shared funding support of various project components.

The ICDR has adopted strategies that will support individual agencies in achieving their goals. The first major strategy is to maintain effective subcommittees in critical areas. The second strategy is to increase the flow of information to all participating agencies. The third strategy is to develop collaborative research and training agendas.

The ICDR has three subcommittees: the ICDR Medical Rehabilitation Research Subcommittee (co-chaired with the Centers for Disease Control and Prevention and NCMRR), the ICDR Technology Subcommittee (co-chaired with the National Science Foundation), and the long-standing Interagency Subcommittee on Disability Statistics (co-chaired with the National Center for Health Statistics).

Each ICDR subcommittee plans and directs the development of an informational database of federal (and other) research in the pertinent area. This may be a compendium of projects or products or an electronic database that can be updated and accessed. For example, the ICDR Technology Subcommittee sponsored the preparation of the *Compendium of Federal Technology that Benefits People with Disabilities* (1998). This compendium contains abstracts of research projects, other technology activities, and technology transfer activities of member agencies—all available on the World Wide Web.

Participation by ICDR Committee and subcommittee members in critical activities of other agencies is a major step toward increasing awareness and collaboration in the field. NIDRR has invited many representatives of the other agencies to participate in peer review panels, long-range planning, priority development, and its new process of NIDRR program reviews that assess the work of NIDRR centers. Jointly developed priorities and shared funding of projects have resulted from these processes. For the future, the ICDR will continue to meet quarterly, hold annual public hearings, provide administrative support for the three subcommittees, and provide an annual report to the president and the Congress.

Program Evaluation and Performance Review

In the past year, NIDRR has begun a process of intensive review for all RRTCs and RERCs during their funding cycles. It has also developed a set of measures in accordance with the Government Performance and Results Act (GPRA) that it will implement to link program outcomes to agency performance standards. NIDRR program reviews take the form of reverse site visits in which center personnel present research and training outcomes in sessions attended by NIDRR senior staff, staff of related federal agencies, other researchers, consumers with disabilities, service providers, private sector representatives such as

employers or manufacturers, and information brokers. These sessions allow for intensive examination, discussion, feedback, and assessment of each center using the Center of Excellence framework.

In the future, NIDRR will expand its program reviews to other NIDRR programs (Model Systems, Disability Business and Technical Assistance Centers, and Dissemination Projects) and will conduct reviews at least twice in a center's performance period. There will be a formative review early in the funding cycle to examine methodology, create linkages to other entities, and develop specific performance measures and outcomes data requirements. A summative review session will be completed near the end of the grant cycle to assess outcomes and implications for future research.

Program review reports will provide input into assessing how well NIDRR is meeting the objectives and indicators set forth in its GPRA plan. NIDRR, like other federal research agencies, will measure research performance and outcomes in the GPRA context. NIDRR has participated in the Research Roundtable, a cooperative effort of many federal research agencies to develop a coherent strategy for applying GPRA to research. NIDRR has developed a two-part performance measurement strategy, based on approaches discussed at the roundtable. The strategy includes both metric measures of productivity (e.g., the number of refereed publications, citations in the literature, people trained) and qualitative narratives which evaluate the scientific excellence, relevance, and dissemination of a project or a center's activities. Research is a lengthy and sometimes serendipitous process; it is impossible to predict what even the most productive research will achieve by any given time. Furthermore, a failed hypothesis can be a project success. At the same time, NIDRR and other federal research agencies share the concerns of Congress and the administration that high standards of program performance and accountability for outcomes must be applied to agency-sponsored activities.

Enhancing Peer Review

NIDRR is implementing a project to redesign and improve important features of its peer review process to provide more continuity of evaluations and improved feedback to applicants. These improvements will include standing panels for some competitions, more useful feedback to applicants, more training for members of peer review panels, a process to identify and handle repeat applications, clarifications of funding criteria and processes, and regularly scheduled annual competitions.

Creative Funding Mechanisms

Four goals of NIDRR's management reform are to stimulate more collaborative research, to support some significant longitudinal research without diminishing competition in the program, to increase the frequency of multidisciplinary research, and to provide grantees with the flexibility to make rapid responses to new scientific and technological developments while maintaining program accountability. Periodic competition ensures the vitality of the program and its openness to new ideas. NIDRR will develop marketing strategies and capacity-building that will expand participation in disability research by leading scientists and innovators, individuals with disabilities, and those from diverse backgrounds.

Currently, collaborative research is implemented in the form of shared protocols and common databases, or in the more diffuse form of subcontracting for discrete parts of a whole. While subcontracting for outside expertise is often convenient, closer working partnerships are to be encouraged. Grantees find the current mechanisms for collecting common data to be administratively and fiscally cumbersome. NIDRR will explore other strategies to promote collaboration, including earmarking funds specifically for collaborative research projects, authorizing grantees to reserve a portion of their centers' funds to support collaborative efforts, and creating coordinating centers in some subject areas.

Disability is a complex, dynamic, and long-term phenomenon. Understanding the course of disablement, rehabilitation, and adaptation frequently requires collection of data over extended time periods. Within the general 60-month limit on grant periods, NIDRR will look for ways to support longitudinal studies in those instances of critical importance. Two mechanisms may be used. NIDRR may create administrative exceptions or create managerial consortia that can transfer the research effort beyond five years. The latter approach might be achieved through the contract mechanism in which the government has clear ownership of all products.

While single-discipline research is important, implementing the new paradigm of disability in research will demand the simultaneous and synergistic attention of many disciplines. In most fields, there is little academic or practical incentive for interdisciplinary research. Indeed, interdisciplinary research tends to become "non-disciplinary" (i.e., nonscientific) research if the underlying theories, assumptions, techniques, and analytical methods are not clearly specified and if the relation to the theoretical and methodological base of each involved discipline is not clearly stated.

NIDRR will promote inter-disciplinary research, if appropriate, through program requirements, selection criteria, and new training approaches.

Knowledge develops rapidly in some fields, and certain shifts or breakthroughs in medicine, technology, or public policy can present opportunities for improvement in the lives of people with disabilities if these changes are addressed immediately. Conversely, some emerging technologies may present barriers to people with disabilities if they are not addressed rapidly. For example, an employed person with a disability may no longer be able to perform a computer job, if new technologies are inaccessible. Thus, NIDRR is developing a systematic process for grantees to direct resources to capitalize on these unforeseen opportunities while maintaining accountability and productivity.

International Research

Background. The Rehabilitation Act of 1973, as amended, (Sec 204 (b)(6)), states that the director of NIDRR is authorized to

> *conduct...a program for international rehabilitation research, demonstration, and training for the purpose of developing new knowledge and methods in the rehabilitation of individuals with disabilities in the United States, cooperating with and assisting in developing and sharing information found useful in other nations in the rehabilitation of the individuals with disabilities and initiating a program to exchange experts and technical assistance in the field of rehabilitation of individuals with disabilities with other nations as a means of increasing the level of skill of rehabilitation personnel.*

NIDRR's international activities are linked to (1) improving the skills of rehabilitation personnel in America through international data, (2) generating international research, which provides needed data, (3) seeking international collaborations for the development of assistive technology, and (4) strengthening disability leadership globally.

NIDRR has carried out its international authority through a variety of activities, including research projects; exchanges and training of scientists, engineers, and other appropriate personnel; exchanges of scientific and technological information; conferences; the support of databases; and other avenues. Examples of these activities include (1) funding collaborative research centers in India through the United States-India Fund, (2) sponsoring information exchange through support for the World Wide Web Initiative with the National Science Foundation, (3) supporting exchange of disability and rehabilitation

experts in issues affecting women with disabilities, and (4) conducting policy studies and forums in areas such as international standards, technology, and special education for the United Nations, the European Union, and the Organization for Economic and Cooperative Development.

Future Plans. The emergence of a true global economy dictates a new role in international activities to promote the well-being of people with disabilities through access to jobs, better technology, and social supports. In addition, the U.S. disability research community desires to share the new disability paradigm internationally. To meet these concerns, NIDRR has established the following priorities:

International Standards. NIDRR will help develop international standards in assistive technology, which will be recognized and debated by regulatory agencies or consortia worldwide. The adoption of these standards will greatly facilitate research exchange and assist consumers in finding appropriate, high-quality products such as wheelchairs and digital telephones.

Joint Research. International collaborative research and development efforts—particularly in assistive technology, universal design, employment, independent living, wellness, and Participatory Action Research—could lead to important discoveries. NIDRR will seek international partners for research projects of mutual benefit. Both partners will share their expertise and project expenses.

Conferencing and Exchange. One of the greatest benefits of an international effort is the effective exchange of information and expertise. NIDRR will create an integrated range of activities to promote the new paradigm in concept and in methodology. International conferences, exchange scholars, and capacity-building will encourage personal contact, hands-on participation in data and research methodology, and practical applications of research results.

Database Expansion. With today's technology, people can gain access to many international databases, providing anyone with access to a universe of information. NIDRR desires to be a catalyst in linking relevant databases globally so that this information is available to any researcher or consumer anywhere on the planet. NIDRR-sponsored information systems will be the gateway to international information-gathering.

Access to Information Technology and Telecommunications. The growing significance of telecommunications and information technology on a global basis has the potential to enable individuals with disabilities to interact with their environments through employment, communication, and participation in

the community. NIDRR will continue efforts to ensure the availability and accessibility of worldwide information technology to people with disabilities.

Management of Intellectual Property

New technologies, especially electronic information media, are stimulating disputes about the ownership of knowledge. This is particularly complicated when the government is financing the development of instruments, databases, or devices. The general principle of grantee right to patent or copyright products, with government right of free use, can be complex to administer. NIDRR will work cooperatively with other federal agencies and grantees to discuss intellectual property guidelines that protect taxpayers' interests in having broad access to knowledge developed with public funds, and yet protect the intellectual property rights of scientists and inventors.

Enhanced Use of Information Technology

NIDRR plans to continue using information technology aggressively to facilitate many aspects of its future activities. Activities include increased and more efficient sharing of research results and data, encouraging more collaborative projects and using common protocols and databases more often. To increase communication with and among grantees, NIDRR will use various communications strategies, including posting information on NIDRR and its grantees on Web sites. NIDRR's accessible Web site, with hypertext links to grantee Web sites, already provides considerable information about NIDRR grantees.

In addition, NIDRR is developing a program database that will provide NIDRR and others with up-to-date information about NIDRR grantees and research findings. This program database will allow analyses of program characteristics, which will result in more efficient management and evaluation of individual projects and the entire NIDRR program. NIDRR also will create linkages for sharing information among centers and projects. These will include bulletin boards, list-servs, and print newsletters. Additionally, NIDRR will continue to sponsor the effective use of teleconferencing, video-conferencing, and emerging telecommunications methods.

Allocation of Resources

The effective allocation of resources is required to achieve NIDRR goals. NIDRR intends to allocate increased resources in four particular areas related to the objectives of its five-year plan. These resources will:

- support the Centers of Excellence, concentrating on large-scale problems;

- support investigator-initiated research projects that use the best ideas emerging from the field;

- expand capacity-building activities, including training researchers with disabilities; and

- develop funding opportunities for collaborative projects.

NIDRR's RRTC program will restructure from a format of many small centers, which handle a limited scope of work, to more substantial centers. The new centers will have the capacity and flexibility to address emerging problems by working across disciplines and disabilities. The change—a complex and time-consuming effort—will involve redirecting some existing resources while protecting valuable research capacity. To continue the success of NIDRR's field-initiated research project program, NIDRR is increasing the number and size of its awards to ensure that excellent researchers continue to pursue this funding opportunity.

NIDRR also plans to review and expand its training activities to foster the continued development of excellent researchers, especially individuals with disabilities, for the disability research endeavor. In addition, NIDRR plans to develop a training database to identify and track people trained in NIDRR's programs and their participation in the disability and rehabilitation fields. The training database will help facilitate the development of a trainee network that will include a Web site; a list-serv for people who participate in NIDRR training programs; and a directory of current and past trainees, scholars, and fellows. This network will contribute to more opportunities for in-person presentations and interactions among NIDRR trainees.

Continuous Participatory Planning

NIDRR will formalize an ongoing process for reviewing and revising the *Long-Range Plan* on a periodic basis, and for ensuring that meaningful annual priorities are crafted based on the plan. This process will involve:

- establishing agenda-setting work groups in each of the outcome areas designated in the plan. These work groups will meet periodically and will be responsible for substantive recommendations, in their respective areas, for both annual priorities and new five-year goals;

- holding at least one public hearing each year. This hearing, which will focus on one substantive area, will evaluate current work and identify future needs in that area. These hearings

will be held in different parts of the country, and will take advantage, where possible, of videoconferencing or satellite broadcasting techniques to allow the hearings to be available to more people nationwide. NIDRR will seek organizations active in the particular substantive areas to cosponsor the hearings;

- convening ad hoc focus groups in subject areas that need further exploration before including them as an annual priority;

- using both internal and external participants to develop a combined Strategic/Program Plan and beginning that process two years in advance of the expected products; and

- evaluating NIDRR performance under GPRA, in part to determine whether annual priorities are derived from and are consistent with the plan.

NIDRR will assess the progress of its continuous planning effort. Then, NIDRR will convey this information in an annual report to the Congress.

Appendix A. Abbreviations and Acronyms

ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
ADLs	Activities of Daily Living
ARRT	Advanced Rehabilitation Research Training Center
CPS	Current Population Survey
CRPs	Community-Based Rehabilitation Programs
DHHS	Department of Health and Human Services
FIM	Functional Independence Measure
GPRA	Government Performance and Results Act
IADLs	Instrumental Activities of Daily Living
ICDR	Interagency Committee on Disability Research
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
IDEA	Individuals with Disabilitites Education Act
IOM	Institute of Medicine
JTPA	Job Training Partnership Act
NARIC	National Rehabilitation Information Center
NASA	National Aeronautics and Space Administration
NCD	National Council on Disability
NCMRR	National Center for Medical Rehabilitation Research
NHIS	National Health Interview Survey
NIDRR	National Institute on Disability and Rehabilitation Research
NIH	National Institutes of Health
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitative Services
PAS	Personal Assistance Services
RACs	(state) Rehabilitation Advisory Councils
RERC	Rehabilitation Engineering Research Center
RRTC	Rehabilitation Research and Training Center

RSA	Rehabilitation Services Administration
SBIR	Small Business Innovative Research
SIPP	Survey of Income and Program Participation
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
VR	Vocational Rehabilitation
WHO	World Health Organization

Appendix B. Planning Process and Participants

To develop a clear, comprehensive plan that meets the needs of the disability community and advances scientific knowledge, NIDRR implemented a collaborative planning process with its many constituents. The planning process was characterized by diversity with varied avenues of input available to a wide range of parties interested in NIDRR's programs. NIDRR solicited input from individuals with disabilities, researchers, service providers, advocates, disability organizations, professional organizations, and individuals who are traditionally underserved.

Steering Committee

In 1995, NIDRR created a Long-Range Plan Steering Committee to consult on the development process. The committee consisted of 15 experts from the constituent community who brought diverse perspectives and experiences to the process. The committee met formally four times in one year and provided other assistance as needed. The major task of the committee was to review input from other sources and make recomendations to NIDRR concerning the plan's design and future planning activities. Appendix C lists the steering committee members.

Public Hearing

A public hearing was held in Washington, D.C., to gather information related to research needs and opportunities for the development of a long-range plan for coordinated research in four areas of disability research: medical and technology rehabilitation, employment, independent living in the community, and capacity-building.

Clifford Brubaker, chair of NIDRR's Long-Range Plan Steering Committee, and Katherine Seelman, director of NIDRR, co-chaired the hearing. Witnesses had a broad range of perspectives on disability; they included people with disabilities and their family members, advocacy organizations, professional organizations, universities, and service delivery organizations. Representatives from the disability media attended the hearing and published articles about it. Written testimony was accepted for 30 days after the hearing.

Witnesses raised a number of shared concerns in all four areas of disability-related research. These included:

- Meaningful involvement of individuals with disabilities and their families in research-related activities and closer linkages to community-based organizations.

- Dissemination of research results to service providers, consumers with disabilities, and policy-makers to maximize the impact of the findings on the lives of people with disabilities.

- Use of collaborative, interdisciplinary, and multi-site research to better address the complex needs of individuals with disabilities.

- Investigation of the effects of new service delivery mechanisms on people with disabilities.

- Outcomes research in all program areas to help ensure continued service to people with disabilities in this era of accountability.

- National-level data sets describing people with disabilities and their lives, particularly individuals with disabilities from diverse ethnic and racial backgrounds, to support program and policy advances.

- Assessment of the impact of the ADA on independence, employment, and community integration.

Commissioned Papers

NIDRR commissioned papers in eight subject areas to provide scholarly background for the *Long-Range Plan*, including a summary of the state-of-the-art in rehabilitation and an analysis of the research needs and opportunities in each area. NIDRR then held a series of workshops on each topic area to solicit feedback on the draft papers and to discuss future research directions. Participants included paper authors, federal representatives, researchers, and servicer providers, including individuals with disabilities and individuals from diverse backgrounds. A list of paper authors and workshop participants follows this summary. In addition, all of the commissioned papers were available to all NIDRR grantees on Web sites and through list-servs for review and comment.

Other Input

NIDRR also considered input from the National Council on Disability, the Interagency Committee on Disability Research, and a myriad of consensus conferences and symposia on topics ranging from employment, income supports, managed health care, technology policy, telecommunications, and the research infrastructure that were sponsored by NIDRR, other government agencies, universities, advocacy groups, and private industry.

Publication of the Plan

NIDRR published a proposed *Long-Range Plan* in the *Federal Register* on October 26, 1998, and invited comments from the public. Subsequently, NIDRR published a revised version in the *Federal Register* on August 20, 1999, that included an analysis of, and response to, the public comments. On December 7, 1999, NIDRR published the final *Long-Range Plan*, which replaced the previous version.

Long-Range Plan Workshop Series Author and Participant List

Authors of commissioned papers are indicated by boldface type.

Workshop on Employment

Henry McCarthy
Louisiana State University

Michael Millington
Louisiana State University

Douglas C. Strohmer
Louisiana State University

David C. Stapleton
The Lewin Group

Becky Hayward
Research Triangle Institute

Clifford Brubaker
University of Pittsburgh

Suzanne Bruyere
Cornell University

Phil Flench, CEAP
Washington Business Group on Health

Mark Hill
Virginia Commonwealth University

David Johnson
University of Minnesota

David Miller
South Dakota Rehab Services

Ruth Royal-Hill (deceased)
District of Columbia Rehabilitation Services Administration

Tom Seekins
The University of Montana

David Vandergoot
Center for Essential Management Services

Douglas Watson
University of Arkansas

Edward Yelin
University of California-San Francisco

Workshop on Physical Medicine and Restoration

Dudley S. Childress
Northwestern University
Rehabilitation Institute of Chicago

Samuel L. Stover, M.D.
University of Alabama at
Birmingham

Bruce M. Gans, M.D.
Rehabilitation Institute of Michigan

Murray Goldstein, M.P.H, D.O.
United Cerebral Palsy Research
and Educational Foundation

Marvin Brooke, M.D.
Tufts New England Medical Center

Chukuka S. Enwemeka
University of Kansas Medical Center

Thomas Findley, M.D.
UMD NJ

Wayne Gordon
Mt. Sinai Medical Center

Margaret Stineman, M.D.
University of Pennsylvania

Sandra Welner, M.D.

Workshop on Rehabilitation Engineering and Technology

Douglas A. Hobson
University of Pittsburgh

Richard A. Foulds
University of Delaware

Lawrence A. Scadden
National Science Foundation

Ronald L. Mace, FAIA
Barrier Free Environments Inc.

Nell Bailey
RESNA

Don Barrett
OSERS
U.S. Department of Education

Diane Bryen
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Alexandra Enders, OTR
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Judith E. Harkins
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Jane Hauser
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Clifford Lanham

A. Keith Miller
Sandia National Laboratory

John Nelson
Rehabilitation Services Administration

William Paul
United Technologies Corporation

William Peterson
National Rehabilitation Hospital

Doris Rouse
Research Triangle Institute

Sheldon Simon, M.D.
Ohio State University Hospital

Gregg Vanderheiden
Trace Center/University of Wisconsin

Workshop on Independent Living

Corrine Kirchner
American Foundation for the Blind

Simi Litvak
World Institute on Disability

Adrienne Asch
Wellesley College

Fabricio Balcazar
University of Chicago-IL

Sharon Barnartt
Gallaudet University

Michael Donnelly
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Carol J. Gill
Health Resource Center
Rehabilitation Institute of Chicago

Harlan Hahn
University of Southern California

Margaret A. Nosek
Baylor College of Medicine
Center for Research on Women with Disabilities

Anita Silvers
San Francisco State University

John Youngbauer
University of Kansas

Workshop on Community Integration

Judith A. Cook
University of Illinois at Chicago

Jessica A. Jonikas, M.A.
University of Illinois at Chicago

Charlie Lakin
University of Minnesota

Joseph G. Hollowell, M.D., M.P.H.
Centers for Disease Control and Prevention

William Anthony
Boston University
Center for Psychiatric Rehabilitation

Mary Ann Beall

David Braddock
University of Illinois, Chicago

Neil Brown
CMHS

Sharon Davis
The Arc

Thomas K. Gilhool, Esquire
Public Interest Law Center of Philadelphia

Wayne Gordon
Mt. Sinai Medical Center

Pat Laird, J.D.
Administration on Developmental Disabilities

Geronimo Robinson
Community Residences

Patti Wilson
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Workshop on Disability Policy and Services

Gerben DeJong
National Rehabilitation Hospital Research Center

Bonnie O'Day
National Rehabilitation Hospital Research Center

Donald E. Galvin
Commission on Accreditation of Rehabilitation Facilities

James R. Knickman
Robert Wood Johnson Foundation

Barbara Altman
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Fred Collignon
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Diane Golden
Missouri Assistive Technology

Ken Hurdle
Senate Office of Research
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Debbie Kaplan
Issue Dynamics Inc.

Clifford Lanham

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Kay Schriner
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Richard Scotch
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Beverlee Stafford
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David Stapleton
The Lewin Group

Sara Watson
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Jane E. West
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Ilene Zeitzer
Social Secuirty Administration Office of Disability

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Laura Edwards
Pennsylvania College of Optometry

Ronald L. Mace, FAIA
Barrier Free Environments,Inc.

Samuel L. Stover, M.D.
University of Alabama at Birmingham

Peter Caws
George Washington University

Beth Haller
Towson State University

Cyndi Jones
Mainstream Magazine

Kym King
Media Development Group

Don Olson
Rehabilitation Institute of Chicago

Elaine Ostroff
Adaptive Environment Center

Alfonso B. Perez
Fiesta Educativa

Kerry Sperry
Research America

Susan Stoddard
InfoUse

Thomas Stripling
Paralyzed Veterans of America

Glenda V. Such, M.Ed.
Abilitech

Steven J. Taylor
Syracuse University

John D. Westbrook
National Center for the Dissemination of Disability Research

Workshop on Capacity-Building

David B. Gray
Washington University

Harley E. Flack
Wright State University

Max J. Starkloff
Paraquad

Kate Pew Wolters
Steelcase Foundation

M. Carolyn Baum
Washington University Medical School

Carole Burnett
Howard University

Alexandra Enders, OTR
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Fredrick E. Menz
University of Wisconsin-Stout

Marian A. Minor, PT
University of Missouri at Columbia

Jerry C. Parker
University of Missouri at Columbia

David Roberts
University of Missouri at Columbia

Virginia W. Stern
American Association for the
Advancement of Science

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Appendix C. Steering Committee Members

Clifford Brubaker (chair) is the dean of the School of Health and Rehabilitation Sciences at the University of Pittsburgh. Prior to this position, he was a professor at the University of Virginia for 18 years. He is a nationally known researcher in seating and mobility and a leader in assistive technology and rehabilitation engineering. He is a founding member of the Rehabilitation and Assistive Technology Association (RESNA) and served as its president in 1993–94. He has received patents for several inventions. Brubaker holds a Ph.D. in exercise physiology.

Robert H. Bruininks is the executive vice president and provost of the University of Minnesota and a professor of educational psychology. He has long-standing interests in educational evaluation and accountability, school-linked services, and strategic planning and educational reform. He established The Institute on Community Integration, a university-affiliated program on developmental disabilities, in 1985 to provide interdisciplinary training, exemplary services, and information and applied research on behalf of people with developmental disabilities and their families. Bruininks holds a Ph.D. in educational psychology.

Ricardo R. Fernández is president of Herbert H. Lehman College, a four-year liberal arts college of The City University of New York. He has held academic and administrative positions at Marquette University and the University of Wisconsin-Milwaukee, and served as a Fellow of the American Council on Education. His research interests include educational equity and the recruitment, retention, and advancement of minority students, faculty, and academic staff in higher education. Fernández holds a Ph.D. in romance languages from Princeton University.

James Paul Firman is president and CEO of the National Council on the Aging Inc. Firman's previous positions include president of the United Seniors Health Cooperative and senior program officer at the Robert Wood Johnson Foundation. He is a widely recognized expert and consumer advocate on many issues affecting older persons, such as home care, long-term care, health insurance and financing issues, and intergenerational programs. Firman has an Ed.D. in education from Columbia University.

Harley E. Flack (deceased) was the president of Wright State University. Flack was previously provost and executive vice president at Rowan College of New Jersey and vice president for academic affairs and dean of the faculty at the State

University of New York at Old Westbury. From 1974-87, Flack served as the founding dean and professor of the college of Allied Health Sciences at Howard University. He also served as a strategic planning consultant for more than 25 institutions in the United States. Flack was president of the National Society of Allied Health and held a Ph.D. in counselor education from the State University of New York at Buffalo.

Donald E. Galvin is president and CEO of the Commission on Accreditation of Rehabilitation Facilities, the preeminent standards-setting and accrediting body promoting quality services for people with disabilities. From 1989–93, Galvin was the vice president for programs of the Washington Business Group on Health and director of the Institute for Rehabilitation and Disability Management. He was associate superintendent of education for the Michigan Department of Education and also served as the director of its Bureau of Rehabilitation Services. Galvin has a Ph.D. in counseling and guidance.

Murray Goldstein is the medical director of the United Cerebral Palsy Research and Educational Foundation and is the interim executive director of the United Cerebral Palsy Associations of the United States. He was formerly the director of the National Institute of Neurological Disorders and Stroke of the National Institutes of Health and assistant surgeon general in the United States Public Health Service. Dr. Goldstein is recognized internationally as a leader in the clinical, scientific, and science administration aspects of disorders of the nervous system.

Joseph G. Hollowell, Jr., M.D., is the medical chief of the Office of Disability and Health at the Centers for Disease Control and Prevention. He is the former chief of the Developmental Disabilities Branch of the Division of Birth Defects and Developmental Disabilities. He is board-certified in pediatrics and has a master's in Public Health from the University of California-Berkeley. He is a nationally recognized expert on low-birthweight infants and children with disabilities. His professional interests include the study of growth in children, pediatric endocrinology, and issues surrounding the definitions, understanding, and prevention of disabilities.

James R. Knickman is vice president at The Robert Wood Johnson Foundation, a national philanthropy that awards grants focusing on efforts to improve the health and health care of Americans. Knickman directs grantmaking programs in health policy research, evaluation of innovations related to health care delivery and health promotion, and care received by the chronically ill. Prior to joining the foundation, Knickman was a professor of Health Administration at New York University's Robert F. Wagner Graduate School of Public Service. Currently, he serves on the Board of Trustees of the Robert Wood Johnson University Hospital.

Knickman received his Ph.D. in public policy analysis from the University of Pennsylvania.

Simi Litvak is director of the Research and Training Center on Personal Assistance Services at the World Institute on Disability (WID) in Oakland, Calif. Formerly the research director of the Research and Training Center on Public Policy in Independent Living at WID, Litvak is a nationally known expert in independent living and personal assistance. She has 30 years of experience in the disability field as a teacher, researcher, policy analyst, policy-maker, and rehabilitation professional. Most recently she served as a member of President Clinton's Health Care Reform Task Force. Litvak holds a master's degree and a Ph.D. in studies in behavioral disabilities from the University of Wisconsin-Madison.

Ronald L. Mace (deceased) was a nationally recognized architect and product designer. He was president of Barrier Free Environments Inc. in Raleigh, N.C., a firm that specializes in design for disabled and older people. He also was director of the Center for Universal Design at the School of Design at North Carolina State University. He was elected to the College of Fellows for the American Institute of Architects for his contribution to the profession in promoting accessible and universal design. He had received numerous awards, including the Distinguished Service Award of the president of the United States for long-term contributions to furthering the rights and independence of people with disabilities.

Audrey L. McCrimon is the assistant secretary of the Illinois Department of Human Services. As the assistant secretary, McCrimon directs the agency's core training strategies, customer service and provider assistance, and Americans with Disabilities Act activities. Prior to becoming assistant secretary, McCrimon had been the director of the Illinois Department of Rehabilitation Services, an agency serving 200,000 state residents with disabilities. Before joining the state government, McCrimon served as deputy commissioner on disability for the Chicago Department on Aging and Disability and was nominated by President Clinton in 1994 to serve on the National Council on Disability. McCrimon holds a master's degree in education from Northern Illinois University.

Lawrence A. Scadden is senior program director for the National Science Foundation's Program for Persons with Disabilities. Previously, Scadden served as director of Technology Application Programs for the Electronic Industries Foundation. He served as the first deputy director of the National Institute on Disability and Rehabilitation Research. Scadden is a nationally known expert on technology applications for people with disabilities and the design of accessible mass market electronic products. Scadden holds a master's degree in

experimental psychology and a Ph.D. in visual sciences from the University of the Pacific.

Max J. Starkloff is the founder and president of Paraquad Inc. Starkloff was co-founder and elected president of the National Council of Independent Living from 1983–85. He was appointed to the president's Commission on White House Fellowships by President Clinton in 1993. Mr. Starkloff is an internationally recognized leader in independent living and has received acclaim from several humanitarian groups.

Samuel L. Stover, M.D., served as medical director of the Spain Rehabilitation Center, project director for the Research and Training Center on Spinal Cord Injury, and director of the National Spinal Cord Injury Statistical Center. Dr. Stover is past president of the American Spinal Cord Injury Association. In June 1994, he retired as chairman of the Department of Rehabilitation Medicine and was named Professor Emeritus. He is a nationally recognized expert in urologic management of persons with spinal cord injury, and skin and pulmonary complications following spinal cord injury. Dr. Stover holds a medical degree in pediatrics from the Jefferson Medical College.

Kate Pew Wolters was the Board Chair of the Steelcase Foundation, the corporate foundation of Steelcase Inc., the world's largest manufacturer of office furniture. Prior to assuming this position, she served as executive director of the foundation. She also has served as the director of the Grand Rapids Center for Independent Living and as a clinical social worker. Wolters was a presidential appointee to the National Council on Disability.

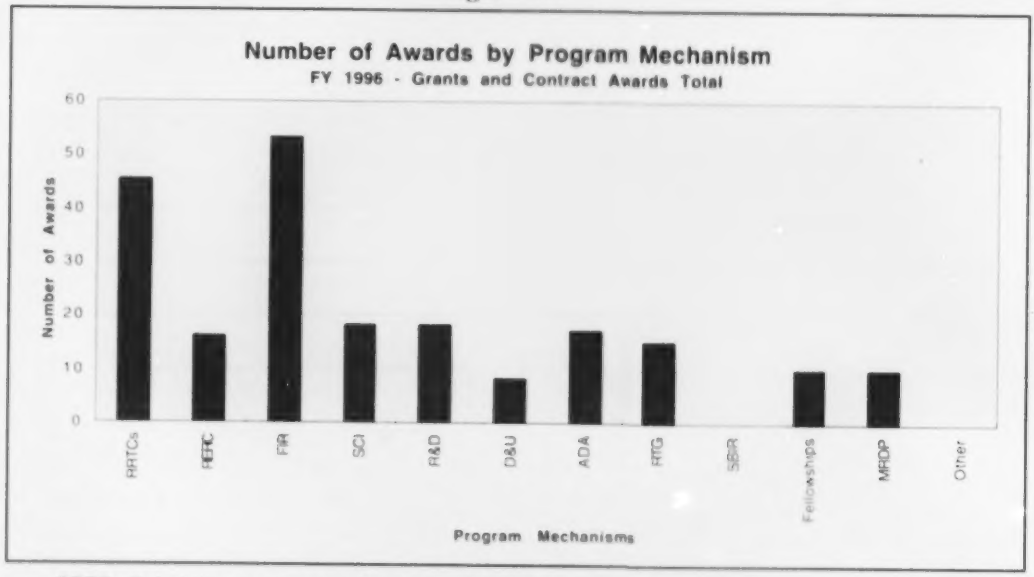
Appendix D. NIDRR Program Mechanisms and Funding Patterns

NIDRR operates a number of program mechanisms to support research and related activities as authorized by the Rehabilitation Act. These mechanisms vary in purpose, duration, and resource allocation. Rehabilitation Research and Training Centers (RRTCs) and the Rehabilitation Engineering Research Centers (RERCs) are the primary recipients of NIDRR resources. As depicted in figure 1.2, these programs received 22.8 percent and 10.78 percent, respectively, of the $70 million appropriated to NIDRR in fiscal year 1996.

Support of RRTCs is specified in the statute. RRTCs are funded to conduct coordinated and advanced programs of research, training, and information dissemination in general problem areas that are specified by NIDRR. RRTCs are expected to be multidisciplinary; involve disabled consumers and their families; provide advanced research training, as well as training for rehabilitation practitioners, consumers, and families; and provide undergraduate education. RRTCs are designed to be national Centers of Excellence and resources for the disability and rehabilitation field, providing information and technical assistance to a broad constituency. Each RRTC is typically funded for five years with an option to recompete. In fiscal year 1996, there were 45 RRTCs. The average annual base award was $507,000, with a range of funding from $400,000 to $700,000. Some of the topic areas of RRTCs include secondary complications in spinal cord injury; community integration of people with traumatic brain injury (TBI); mental retardation; or mental illness; vocational rehabilitation outcomes; independent living; interventions for children with severe behavior problems; aging with a disability; and personal assistance services.

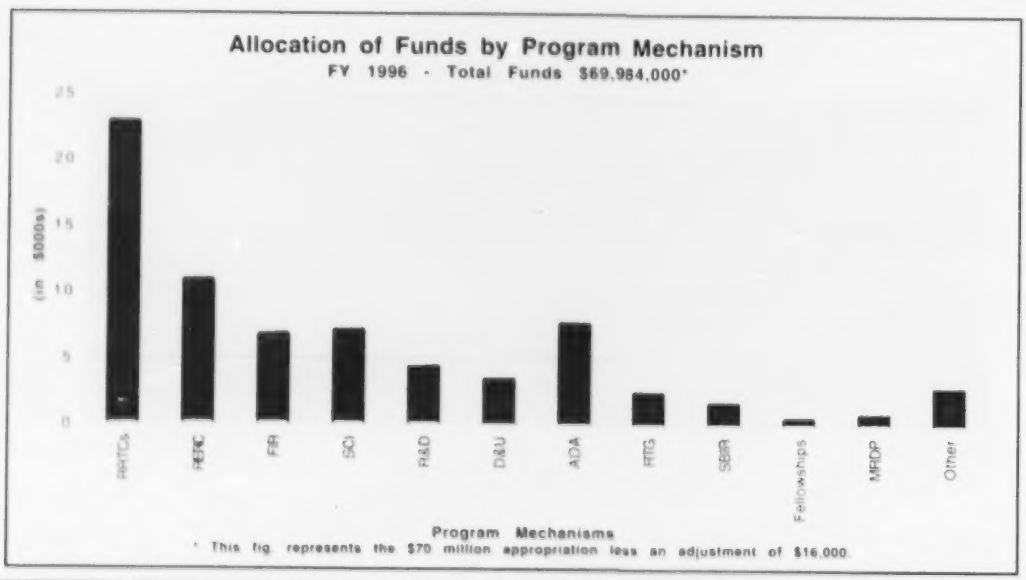
RERCs also are provided for in the legislation, and are expected to conduct research of an engineering and technological nature to design, develop, and test technologies, equipment, assistive devices, and methods to remove environmental barriers, and innovative models for rehabilitation technology service delivery. The 1992 amendments to the Rehabilitation Act specified an increased emphasis on training and collaboration with rehabilitation service delivery efforts. NIDRR also expects RERCs, where appropriate, to promote the transfer of new rehabilitation technologies and engineering knowledge into the manufacturing, marketing, and distribution processes of industry. In fiscal year 1996, NIDRR funded 16 RERCs at a total cost of $10,764,000; the average award was $673,000 annually. These are nearly always five-year awards, with the potential to recompete. Some of the topical areas of the RERCs include prosthetics and orthotics, wheeled mobility, hearing enhancement, communication, computer adaptations, and telecommunications.

Figure 1.1



RRTCs-Rehabilitation Research and Training Centers
RERC-Rehabilitation Engineering Research Centers
FIR-Field-Initiated Research
SCI-Spinal Cord Injury Systems
R&D-Research and Demonstration
D&U-Knowledge Dissemination and Utilization
ADA-Technical Assistance on Americans with Disabilities Act
RTG-Research Training Grants
SBIR-Small Business Innovative Research
Fellowships-Fellowships
MRDP-Minority Research and Development Program
Other-Conferences, planning, evaluation, priority and peer review, and more

Figure 1.2



The statute also provides for directed research, carried out in the Research and Demonstration (R&D) Projects program, a program of discrete research grants directed toward solving specific problems identified by NIDRR. The Knowledge Dissemination and Utilization (KD&U) Program, and the program of Technical Assistance to Facilitate Implementation of the Americans with Disabilities Act, better known as the Disability and Business Technical Assistance Centers (DBTACs), are also examples of NIDRR-directed priorities in discrete project areas. These programs support grants for periods of three to five years, and together accounted for $15 million in 1996. Examples of R&D projects include development of model systems for traumatic brain injury and burns, the emerging universe of disability, and unique issues of women with disabilities. KD&U projects include the National Center for Dissemination of Rehabilitation Research, a national clearinghouse on rehabilitation information, and a resource center on integration and mental retardation.

The law also provides for two capacity-building programs—Fellowships and Advanced Rehabilitation Research Training Grants (ARRTs). Fellowships are awarded to individuals in various stages of their careers to support one year of independent research in a selected area of disability and rehabilitation. ARRTs are awarded to institutions of higher education to support advanced training in research in any discipline related to disability and rehabilitation. These grants which are typically for five years, fund stipends to trainees, mentoring, didactic instruction, hands-on research experience, and opportunities for presentation and publication.

The statute provides that NIDRR support a service demonstration and research program directed at developing and evaluating improved methods and systems of care for individuals with spinal cord injuries, the Model Demonstration Projects for Spinal Cord Injury, known commonly as the SCI Model Systems. Appropriations language requires that $7 million be allocated to this program. There are currently 18 model systems, with broad geographic distribution serving people in inner city, rural, and suburban areas.

NIDRR created a program of field-initiated (FI) research in 1984 in response to recommendations from the field. The purpose of this program is to encourage researchers to submit research and development projects outside those specified by NIDRR, to supplement and complement NIDRR's directed research portfolio, and to address research issues in promising and innovative ways. The level of resources allocated to this program has varied substantially over the years, but in fiscal year 1996, 53 FI grants, including 20 new awards, were made for $6.5 million, or close to 10 percent of the NIDRR appropriation. NIDRR has begun to increase its investment in the FI Program in response to recommendations from the field. FI research projects cover all aspects of NIDRR's domain, including

employment, independent living, medical rehabilitation, development of new technologies, all disability populations, and a full range of methodologies.

To relate NIDRR's current pattern of funds allocation to the goals that underlie this plan, an effort has been made to classify NIDRR's current projects according to the major subject areas (health and function, access and functional independence through technology, employment, and independent living and community integration), plus policy research, capacity-building, and knowledge dissemination. This classification was complicated enormously by the fact that NIDRR's projects and centers reflect the multifaceted nature of disability and the holistic nature of rehabilitation. Many, if not most, projects and centers are directed at solutions to problems in more than one subject area. For example, Spinal Cord Injury Model projects are concerned with health and function, return to the community, and employment. This classification overlooks the large amount of resources directed to knowledge dissemination and capacity-building, and to some extent policy research, in all centers and projects. However, it was determined that a non-duplicative representation of the allocation of funds was essential; therefore, arbitrary decisions were made to classify each center or project in only one subject area. Programs that included either health and function or technology development were classified in those areas, regardless of their other components. However, due to the substantial work on independent living and employment done in the Spinal Cord Injury Model projects, one-quarter of their funds were counted in each of these two categories and one-half in health and function. As one of its research management improvements, NIDRR is constructing a database that will permit more precise calculations of resource distributions. Table 1 depicts this classification by topical area.

Table 1

Percentage of Grant and Contract Funds by Topic Area Fiscal Year 1996

Topic Area	Percentages
Health and Function	20
Technology for Access and Function	20
Employment	15
Independent Living and Community Integration	21
Associated Research Areas	3
Knowledge Dissemination and Utilization	15
Capacity-Building	6
	100 percent

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